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Constitution of the market through social media: Dialogical co-production of medicine in a virtual health community organization

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CONSTITUTION OF THE MARKET THROUGH SOCIAL MEDIA: DIALOGICAL CO-PRODUCTION OF MEDICINE IN A VIRTUAL HEALTH COMMUNITY ORGANIZATION

A Dissertation

by

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CONSTITUTION OF THE MARKET THROUGH SOCIAL MEDIA: DIALOGICAL CO-PRODUCTION OF MEDICINE IN A VIRTUAL HEALTH COMMUNITY ORGANIZATION

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ABSTRACT

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This research explores new systems of marketing, and new roles and relationships of organizations and consumers developing in healthcare as a result of transformations occurring in technology, consumer/marketer value systems, forms of discourse and institutional roles. Inspired by observations from a Medicine 2.0 community organization, which turn social networking into a business phenomenon – PatientsLikeMe (PLM) – I explore how such systems develop and function and the institutionalizations that reconstitute roles and maintain relationships among actors in these systems through netnographic research. That is, (1) why and how patients in PLM participate in the social co-production of medical knowledge and experience, and (2) how the ‘community’ organizes roles and relations, and institutionalize ‘sharing’ in healthcare where privacy dominates relations. Findings articulate a dialogical approach to organizing roles and relations with the dilution of provisioning in this co-mediated market system, which reflects collaborative, connective and communal relations built on dialogues among diverse healthcare actors. From a theoretical vantage point, Foucauldian notions of biopower and govern-mentality are reconsidered in order to articulate why and how such a system may be attracting healthcare actors and maintain their interest and sharing in this community.

DEDICATION

The completion of my doctoral studies would not have been possible without the love and support of my family. My mother Gülşen Kar, my aunt Hatice Kar, my grandmother Emine Kar, and my brother Hakan Vicdan, wholeheartedly inspired, motivated and supported me by all means to accomplish this degree. Thank you for your love and patience.

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CHAPTER I

INTRODUCTION

Transformations are taking place in how consumers feel and think about life and consumption that also affect their behaviors. Enabled by new technologies (Tapscott and Williams 2008) and influenced by recent cultural trends (Fırat 2005; Fırat and Dholakia 1998, 2006; Lyotard 1984; Rose 2007), these transformations affect how consumers organize their relationships with the organizations that they interact with in the market. As a result of these changes, consumers' lives are also reorganized. Since consumers develop new ways of acting and thinking with the cultural changes that are occurring, it is necessary to inquire why consumers, at this point in history, seek these transformations, as well as how they seek out the technologies that enable these transformations.

This research explores new systems of marketing developing as a result of the above mentioned transformations. The new roles and relationships of marketing organizations and consumers are also explored. The purpose is to provide insights into developments in healthcare provision as systems that utilize social networking and engage in reformation/reconstitution in healthcare develop and grow. Previous theories of the market and market relations are revisited in order to understand why and how new perspectives need to be incorporated into our frameworks. Earlier theories articulate the structure of relationships between consumers and organizations they interact with in the market largely in terms of a dialectical process. That is, the consumer and the marketer are constituted in opposition to each other, in a dominant/dominated dialectic. There is unidirectional provisioning envisioned that gives control and primacy to the marketer, hierarchical relations among actors in market systems are proposed, and one way governing of relationships is imagined through frameworks that ‘normalize’ consumers into segments and that seek to maximize profits. This study aims to reflect the dialogical nature of consumer-marketer roles and relations, which presents collaborative, connective and communal characteristics through social media platforms. Not only technological advances but also changing consumer/marketer value systems, forms of discourse and institutional roles create the need for exploration into changing market relations and organizations of business.

This research aims to provide insights into how these dialogical processes originate, develop and function with the effects of social media platforms by exploring a web-based Medicine 2.0 community organization and a social networking site in healthcare, *patientslikeme.com* (PLM). Discovering the (meso/community level) social and cultural dynamics of such a community organization and its impact on healthcare market dynamics will bring attention to the social production of medicine today, articulating relational and role related transformations regarding different healthcare market actors. PLM involves patients, physicians, pharmaceutical companies, healthcare researchers, along with the administrators of the website. PLM is a co-mediated market platform for real-time partnership among these market actors. PLM enables organized decentralization of private health data sharing, and mobilizes market actors as a non-state institution through non-dominating discursive regimes (Rose 2007) (e.g., hope based versus fear based culture, openness versus privacy). Patients actively engage in real-time clinical research and generation of new medical knowledge, and determine their and others’ care along with other healthcare market actors in this community.

Consumer researchers have long discussed the relationship between the consumer and the producer and the insurmountable influence of the ‘market’ on the consumer (Fırat and Dholakia 1998; Slater and Tonkiss 2001). In these debates, one issue of contention is the constitution of the consumer and the producer. For example, different scholars conceptualized the consumer as (1) a sovereign, individualistic, possessive, rational actor (Bagozzi 1975; Kotler 2003), (2) a passive, alienated, obedient, and powerless dupe (Adorno and Horkheimer 1993; Marcuse 1991; Murray, Ozanne and Shapiro 1994), (3) a resisting, subversive and confrontational agent (De Certeau 1984; Fiske 1989; Murray and Ozanne 1991; Peñaloza and Price 1993), or a presenter of alternative life modes (Fırat and Dholakia 1998), and (4) an adopter of emancipatory/liberatory interests in escaping the market (Kozinets 2002a). Some scholars argued that as opposed to the consumer, the marketer is exploiting, powerful, commodifying, and has a central role in co-creation (Terranova 2004; Zwick et al. 2008). Others often conceptualized a hegemonic market thriving on these dialectical tensions or countervailing positions (Holt 2002; Kozinets et al. 2004; Thompson 2004). In addition, it has been argued that the conventional market order serves to institutionalize the roles and relationships among market actors in modern society (Slater and Tonkiss 2001).

Recently, other consumer researchers have acknowledged that the relationship between the consumer and the marketer is a discursive formation enabling the possibilities of joint or collaborative construction (Denegri-Knott 2004; Holt 2002; Slater 1997; Zwick and Dholakia 2004). Therefore, the separate roles ascribed to both the consumer and the marketer in earlier perspectives are partly mitigated. Yet, extreme emphasis on superior/inferior dialectics between the consumer and the marketer is not transcended. Despite the recent trends in marketing, such as those proposing co-production, co-creation of value (Vargo and Lusch 2004), which promote collaboration among actors in market systems (Denegri-Knott 2004; Holt 2002; Slater 1997; Zwick and Dholakia 2004; Kozinets et al. 2004; Thompson 2004), the marketer still has the central role in co-creation; in institutionalizing the ‘proper’ way of conduct and engaging in interactions with consumers to provide what they need and want (Fırat and Dholakia 2006). In addition, some scholars considered co-production or co-creation of value by free, immaterial labor in cyberspace as ways of exploiting and controlling consumers by corporations (Terranova 2004; Zwick et al. 2008). From this perspective, in the capitalist system, co-creation[1] is constituted as a disguise to establish a specific form of government that influences consumption orientations through which consumers provide ‘voluntary’, ‘unwaged’, ‘exploited’, yet ‘enjoyed’ labor – a new form of govern-mentality [2] in Foucault’s (1991) terms.

These views of the market and market relations rest mainly on modern conceptions of power including domination, confrontation (Venn 2007) and unilateral govern-mentality (one way of dictating and imposing). Such perspectives also emphasize maximizing and normalizing discourses by marketers in order to dominate consumers. For example, in healthcare, state institutions and healthcare providers use the discourses of fear of loss of life, normalization of body, maximization of lifespan, and threat of death (Rose 2007), as means to discourage social networking and medical information sharing among patients, and to protect patient privacy. Medical interventions generally involve a top-down approach: Physicians, researchers, pharmaceutical companies and other influentials in the market tell patients what/what not to do and decide what patients need to know. Hence, the human body in modern society has become

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[1] Zwick et al. (2008) suggest that from a Marxist point of view, co-creation of value is considered as the mobilization and exploitation of free, immaterial consumer labor despite its voluntary, affective, and enjoyed characteristics.

[2] The use of the hyphen in the Foucauldian concept of governmentality indicates the broadening of the concept to include any forms of government (e.g., conducting oneself and/or others), not just government in terms of the state, and how and what people who are governed think about the way they are governed in various contexts (Dean 1999).

an object of one-way scrutiny and surveillance by a superior and rational medical gaze (Foucault 1975).

Technological advances (e.g., specifically Web 2.0 and social media) have remediated the superior-inferior dialectics between the physician and the patient. That is, informed patients have become partners with their receptive physicians (Jadad 1999; McGregor 2006). In addition, transformation of social networking (Web 2.0) into a business phenomenon (Tapscott and Williams 2008) has helped to challenge the conventional forms of business, which treat organizations and consumers as distinct entities. In modern market society, organizations were considered as distinct/detached entities from consumers in the market, providing goods/services to satisfy the needs of their target markets (Fırat and Dholakia 2006; Peñaloza and Venkatesh 2006). Yet, as a result of technological transformations, organizations are becoming increasingly less separate from their markets. They serve as systems of real-time processes, whereby performers of the market together discover and design their needs in actual or virtual collectivities (Fırat and Dholakia 1998; Kozinets 2002a).

As recent technologies (Web 2.0 and social networks) enable the transformation of roles and relations among market actors, they also increase the potential for collaboration among actors in market systems that now function in a more complex set of relations. Web 2.0 technologies emphasize innovative, data-oriented, service-centered collaboration, increased levels of user contribution, organization of content through non-hierarchical methods, and increased aspirations of community building, sharing and interaction (Bleicher 2006). Despite conflicting views (Eysenbach et al. 2004, Jadad et al. 2006), Web 2.0 applications in healthcare present a potential to transform the long-dominant top-down approach in healthcare and change patient-healthcare provider roles and relations. As previously mentioned, patients conduct real-time clinical research with other healthcare market actors, and track each others' and their own diseases to manage their and others' care and learning (Jadad 1999) in PLM. Such transformations could decentralize the control and use of personal health data, change the mindset of physicians concerning patients as incompetent and solely as recipients of information and service (Deshpande and Jadad 2006), and bring about institutional change in healthcare toward a mode of collaboration rather than a mode of provision.

Taking a positive and productive approach to consumer-marketer collaboration, Ballantyne and Varey (2004) suggest that the dominant modern marketing principles and practices could be replaced by dialogical interactions. Dominant marketing practices are generally characterized with monological, unidirectional, and hierarchical modes of interaction among market actors, which have given primacy to the control driven and providing marketers. In contrast, dialogical interactions are founded on *dialogue* (Ballantyne and Varey 2004) and *togetherness* among actors in market systems, and emphasize learning and co-creating together, as well as co-determining value in networked relations. As the potentials of different consumer sensibilities (Fırat and Dholakia 1998, 2006; Featherstone 1991; Lyotard 1984), relational and role related transformations are increasingly discussed in the literature, along with transformations in emerging Web 2.0 technologies (Tapscott and Williams 2008), particular examples regarding where and how these transformations are occurring are mostly absent. To close this gap, this research explores if, in PLM that seems to exhibit such potentials, there are robust indicators of how and why such novel organizations of life, business, and relationships among performers in the market form and maintain their existence. Alternative to temporal and local contexts (e.g., Burning Man) where new sensibilities and relations are observed, study of organizations of relations that are more stable and permanent will provide further insights into the processes of origination and continuation.

Consequently, this research seeks to reveal these new forms of organizing roles and relationships; and unconventional forms of business relations among the performers of the market system by seeking answers to the following questions:

1. Why and how do such systems develop and function?
2. What are the forces that originate these new forms of relationships and make people become a part of these systems?
3. What are the institution(alization)s that develop and maintain these new forms of interactions and relationships, make people become a part of these systems and share their private health information in their quest to accelerate medical research and discover cures for life changing diseases?

Adopting a poststructuralist perspective, the dynamics of discourses among community members in PLM[3] will be unraveled, as a new language launches a new way of constituting subjects and their relationships (Foucault 1975, 1977, 1978). The discovery of the constituents of dialogical processes in PLM aims to bring further theoretical insights to understand potential marketing systems and new ways of organizing market relations. In addition, this study will articulate the changes in current healthcare market dynamics as a result of systems that utilize social networking and reconstitute roles and relations in the healthcare market. Foucauldian notions of govern-mentality and biopower will be reconsidered in order to articulate the

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[3] From a poststructuralist perspective, systems are not constituted as a result of material and economic relations but as a constellation of discourses and practices, as a result of the ways individuals and communities culturally and symbolically determine and organize them.

theoretical/conceptual explanations of how and why this new system may be attracting patients and other healthcare actors and (re)organizing their relationships, as well as how their interest and participation in the system are maintained. Consequently, this study will focus attention to the shift from state intervention to the multitude of diverse healthcare market actors in organizing sharing, generation and distribution of private health information. Furthermore, findings of this study call attention to the possibility that PLM contributes to (re)institutionalizing surveillance in healthcare in the form of *biosocial surveillance*, through conducting clinical research and intensifying connectedness among healthcare actors.

CHAPTER II

LITERATURE REVIEW

> If power were never anything but repressive, if it never did anything but say no, do you really think one would be brought to obey it? What makes power hold good, what makes it accepted, is simply the fact that it does not only weigh on us as a force that says no, but it traverses and produces things, it induces pleasure, forms of knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than a negative instance whose function is repression (Foucault 1980, p. 119).

Revisiting Previous Theories of the Market and Market Relations

The ‘market’, a modern institution that organizes human lives and activities according to the economic necessities, and enables human beings to accomplish the grand project of modernity in ways that further the principles of market expansion, was initially conceptualized as a mechanism (Slater 1997). Through this mechanism, consumers and producers manage to exchange their resources without any preceding or ensuing obligations to each other. In this classical economics perspective (e.g., Ricardo 1817, cited in Slater and Tonkiss 2001), the market as a mechanism stands separate from the consumer, for the use of buyers and sellers who meet each other by the aid of this mechanism. In addition, information and opportunity is evenly distributed so that the market can sustain perfect competition among market actors leading to equilibrium (Slater and Tonkiss 2001). Human relationships were also transformed from intimate and informal to instrumental, formal and discrete (Tonnies 1957).

Hence, the social has been extracted from the market, and the market as a mechanism served to emancipate consumers from the restrictions and oppressive obligations that could repress their free will (Russell 1972) and engagement in rational market exchanges. Emancipation was considered an essential condition for individuals to control their own destiny and arrive at the ‘grand future’ in which they achieve their goal of improving human condition. Such accomplishment depended on the capability of individuals to act on their own ‘free’ will (Rorty 1979) and become ‘free’ agents who are able to attain their needs and wants. The market as a mechanism outside of the consumer and the producer then 1) enabled reasoned and calculated economic exchange, 2) promoted maximization and efficiency in exchanges, 3) led to instrumental, formal and discrete relations among the performers of the market, and 4) liberated the consumer as a sovereign actor from the forces that oppress their free will.

As the market mechanism performed these goals, it also led to the growth of *individualization*, *commoditization*, *consumerization*, and *marketization*, along with increased centrality of the economic in modern culture, especially in western societies (Slater 1997). For example, marketization of human interactions enabled consumers to act on their free will and constitute themselves as distinct from others in the market. That is, through the market mechanism, buyers and sellers could freely engage in market exchanges and serve their own ends in a systematic way, without any obligations or prior connections to each other. The market mechanism, through freeing individuals from the obligations that tie her/him to others, and restrictions that prevent individuals from practicing their free agency, also increased the potential of the individual to practice her/his individuality. This ideal of freeing the individual and making it possible to practice her/his individualization through the market also required that (1) the consumers be separated from the production process and present their individuality through consumption practices (Fırat and Dholakia 1998; Slater 1997), (2) and relate to the goods they acquire and consume simply as consumers, leading to the rise of consumerization.

All of these processes, while enhancing the emancipation and individualization of the consumer, have led to the growth of the market institution, which has come to control and organize the lives of consumers while enabling their progress toward taking control of their own destiny and accomplishing their utmost potentials (Fırat and Dholakia 2006). The market as an institution, with its central focus on the economic and disembeddedness from social relations and institutions (Polanyi 1992), became the dominant organizing principle of human lives and relations in modern capitalist society (Polanyi 1992; Slater and Tonkiss 2001). The market in modern society has become the "sole locus of legitimation" (Fırat and Dholakia 1998, p. 90), and excluded the alternative ordering principles or forms of legitimation of society while diminishing the importance of social values in human relations (Birchfield 1999).

Constitution of the Consumer and the Marketer: Reflections from Modern Thought

In modern society, we observe the rise of the dominance of the markets and market exchanges (Bagozzi 1975, Kotler 1972), and the market institution reinforcing *an* order of organizing human lives (Fırat and Dholakia 2006; Slater and Tonkiss 2001). Such an order is characterized with (1) calculation and maximization of utility by agents to secure their self-interest (Callon 1998), (2) possessive individualism (Macpherson 1962), (3) rationality, commodification, and monetarization (also linked to depersonalization, calculation, and quantification), and (4) contractual and corporate links as opposed to organic personal connections (similar to Tonnies' (1957) Gemeinshaft (community) and Gesellshaft (society) distinction) (Slater and Tonkiss 2001). Scholars in marketing and consumer research also discussed consumers' position in this order: Following classical and neoclassical economic theories (e.g., Adam Smith, Keynes, Ricardo), some scholars advocated consumer sovereignty and argued that consumers are in fact free, individualistic and possessive actors who make rational choices (Bettman et al. 1998; Friedman and Friedman 1991), and engage in market exchanges to maximize their utility (Nelson 2002). As also emphasized in marketing text books (Kotler 2003; Kotler and Keller 2007), marketing, the modern business tool of the market, was characterized with consumer centeredness in marketing practices and exchange behaviors (Bagozzi 1975).

Contrary to the scholars (e.g., classical and neoclassical economic thought), who constituted the consumer as a sovereign, autonomous, instrumental and rational actor (Slater 1997), critical theory scholars in consumer research offered two alternative perspectives. Following the Frankfurt School (Horkheimer and Adorno 1993; Marcuse 1991), some emphasized the hegemonic and oppressive nature of the market and argued that consumers are passive and powerless dupes, whose participation in the production process is dictated by corporations (Fırat and Venkatesh 1995), and they are doomed to be dominated by the market (Murray and Ozanne 1991; Murray et al. 1994). Others explored consumers' utmost interest to fight for their agency and their position in the market (Fırat and Venkatesh 1995; Fiske 1989; Price and Peñaloza 1993), and argued that consumers are in fact creative, subversive, agentic and active agents, who use their consumptive activities as means for resistance and emancipation (De Certeau 1984; Fırat and Dholakia 1998; Fiske 1989; Peñaloza and Price 1993). For example, Thompson (2004) suggests that through the organic food movement, the consumer strives to distinguish herself/himself from mainstream scientific medicine, which has extreme focus on regulating and normalizing illness induced imbalances in our bodies through reliance on pharmaceutical and surgical interventions. Conventional physicians legitimize and impose on patients certain ways of well-being and treatment protocols, which lead to countervailing strategies by consumers in order to contest the legitimacy and authority of scientific medicine. Consumers are therefore active and creative agents, who resist the disciplinary power of the market (Kozinets and Handelman 2004). Consumers also resist or emancipate themselves from the oppressive interests of corporations simply by presenting their selves or by doing their own thing (Fırat and Dholakia 1998). For example, Fırat and Venkatesh (1995) suggest that consumer culture is in a transition period from modern to postmodern, in which the growing interest in multiplicity of consumption choices may ultimately liberate people from the market's domination. As consumers adopt a culture that entails presenting alternative ways of being and experiencing the world, which is distinct from the culture imposed on them by the market, they can and will resist and break down the market's dominance. Hence, consumers gain the ability to outflank marketers as constructors of oppositional meanings and ideologies through their consumption practices (Fiske 1989; Peñaloza and Price 1993).

Recent trends in the constitution of the consumer have promoted the idea of consumers becoming co-producers or co-creators of value in the marketplace, and challenged the traditional logic of marketing (see Denegri-Knott 2004; Vargo and Lusch 2004). Some scholars took a more modest stance in articulating consumer-marketer relations, and advocated this participatory and constructive nature of market relations (Holt 2002; Kozinets et al. 2004). For example, Vargo and Lusch (2004) argued that marketing is viewed as a way of provisioning what consumers need, and a process of doing things in interaction with the customer. Consequently, the consumer takes on a more active role in production and becomes a co-producer, especially with the growing technological advancements. These views attract attention to the transformation that corporations can no longer dominate consumers, since the consumer actively partakes in the creation and delivery of value. Nonetheless, the marketer still has the central role in this co-creation process, and the marketer's role has evolved to encompass the exchange of specialized skills and knowledge in provisioning what consumers need and want.

Novel corporate philosophies such as value co-creation (Prahalad and Ramaswany 2004), service dominant logic (Vargo and Lusch 2004), customer relationship management (Day 2000), and customer knowledge management (Gibbert et al. 2002) have all been considered as new ways of governing consumers and exploiting them by giving them a sense of control and freedom in active participation in production (Zwick et al. 2008) with a predetermined agenda (Arvidsson 2006). Hence, in frameworks that articulated consumer-marketer relations, collaboration among the performers of the market system is constituted as a form of appropriation and commodification of the general intellect[4] (Marx 1973; Virno 2004) and experience (Pine and Gilmore 1999) by the market. As consumers engage in and enjoy collective and participatory actions in cyberspace, their enjoyed and productive labor serves as a source to be exploited by the market (Cova et al. 2007; Kozinets 1999; Tapscott and Williams 2008). Hence, corporations continue to extract and co-opt 'free labor' from 'free' consumers and govern them by making them partners in this joint production in the marketplace. Co-creation then serves as a new form of govern-mentality for the marketer to exert control over the consumer (Zwick et al. 2008), since the marketer still has the central role in the co-creation process through the act of provisioning. Co-creation also becomes a radical form of cooptation of consumer resistance by the market (Zwick et al. 2008), yielding again the constitution of the consumer as a docile and managed subject despite the enabling of autonomous consumer creativity. Similar to the Marxian view of the market, these perspectives advocate that in

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[4] General intellect is considered as a Marxian modulation on the idea of a networked collectivity dominant in futurist scholarly work (e.g., Pierre Levy's concept of collective intelligence), which are characterized by technological determinism and philosophical idealism (Terranova 2004).

modern market society, exchanges between market actors are unequal and result in exploitation, alienation and debasement of the consumer, rather than liberation or empowerment of her/him (Slater and Tonkiss 2001). Such perspectives highlight the oppressive interests of the marketer despite the collaboration with the consumer, and overlook the productive capabilities of this collaboration. Scholarly work in the field of marketing and consumer research generally maintains a view that separates consumers and marketers, and their activities, and disregards their interrelations and communities (Peñaloza 2008).

As previously mentioned, scholars, who adopted a more modest position concerning the role of the consumer in the market, have diverged from previous views that perceived market actors in oppositional constitution. They brought forth the alternative view that consumers and marketers have indeed interdependent relationships in the market, and they possess mutual wills (Kozinets et al. 2004). Nevertheless, they conceptualized consumer agency and her/his position in the market to entail resistant and emancipatory motives, on which the market thrives and maintains its hegemony (Holt 2002; Kozinets et al. 2004; Thompson 2004). As Holt (2002, p. 89) puts it, "what has been termed 'consumer resistance' is actually a form of market-sanctioned cultural experimentation through which the market rejuvenates". Moderate perspectives of consumer-marketer relations advocated the discursive nature of this relationship. That is, the individual consumer is "simultaneously objectivized by institutional (market) discourses and disciplinary power and subjectivized by practices of the self" (Denegri-Knott et al. 2006, p. 961). Hence, consumer and marketer exchanges and relations reproduce the market as co-creators of value (Denegri-Knott 2004; Holt 2002), and the market rejuvenates itself and maintains its domination over the consumer. Similar to the Foucauldian view of governmentality, these perspectives designate the ways in which consumer-marketer relations are governed. That is, to govern is "to structure the possible fields of action, and the practice of governing includes governing through technologies of domination as well as governing the self" (Foucault 1982, p. 221). Consequently, governmentality operates simultaneously between external domination (technologies of domination[5]) and self-government (technologies of the self[6]), and entails both a disciplinary and a liberating character (Rose 1999a). As consumers freely practice their selves and identity positions, they also internalize the dominant disciplinary power of corporations.

Even though these perspectives partly moderated the separate roles ascribed to consumers and producers in the market, the dominant/dominated dialectic was still prevalent in explaining consumer-marketer roles and relations. In this dialectical relationship, the consumer constantly fights for her/his agency and tries to liberate herself/himself from the oppressive interests of corporations (Denegri-Knott 2004; Holt 2002; Kozinets et al. 2004; Thompson 2004). Consumer researchers supported this constitution of the consumer with empirical evidence from western societies (Holt 2002; Kozinets 2001 and 2002; Thompson and Troester 2002; Thompson and Arsel 2004). Alternatively, Fırat and Dholakia (2006) advocated the rethinking of consumer agency by recognizing multiple orders rather than a single market order. In agreement with Kozinets (2002a), who advocated that complete emancipation from the market is illusory and temporally and locally bound, they also suggested that resistance to market order could only be short-lived. As each order comes with its own power disparities, which will lead to certain privileged ways of thinking and acting, it constitutes *an order*. Consequently, consumer agency

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[5] Consumers may increasingly practice their subjectivities and engage in self-governing practices, yet their desires and willingness to practice their selves are fueled by and tailored to corporations' self-interests (Rose 1999a), hence leading to another form of domination achieved through governmentality.

[6] Technologies of the self relate to socially constructed mechanisms that enable people to practice and experience their own subjectivity.

is only possible through construction and navigation of multiple orders in collectivities (Fırat and Dholakia 2006).

As observed in the above discussions, scholars have generally assessed the consumer-marketer roles and relations in the market in the dominant/dominated dialectic. In addition, tensions that occur between the consumer and the marketer as a result of this dialectical constitution indicate the utmost desire of the consumer to emancipate herself/himself from the exploitative interests of corporations. The urge to resolve these tensions requires that the consumer engage in power struggles through various strategies. For example, consumers act as active, subversive players and presenters of alternative lifestyles (Fırat and Dholakia 1998; Fırat and Venkatesh 1995; Holt 2002; Murray and Ozanne 1991) or engage in construction of communities (Kozinets 2001; Muniz and O'Guinn 2001; Schouten and McAlexander 1995). Kozinets et al. (2004) also view the consumer as a ludic agent, whose productive performances become a part of the service, yet whose consumption negotiations still indicate a dialectical mode. Consumers constantly struggle for their agency and resist the market order by creating countervailing market systems in response to corporate co-optation (Thompson and Coşkuner-Ballı 2007) or appropriating what the market offers for their own ends (Heath and Potter 2004). This endless pursuit of maintaining "an autonomy from the mainstream market culture" (Fırat and Dholakia 1998, p.157) leads to the constitution of the consumer as a distanced social entity, whose utmost desire is to resist the market order and detach herself/himself from the marketer.

Consequently, the processes in the market result in commodifying the consumer, thriving on oppositions and resistance by the consumer and co-opting them. For example, Thompson (2004) suggests that the organic food movement by natural health advocates is a novel capitalist resource for the rejuvenation of the market. In addition, some scholars conceptualized consumer resistance as an avoidance behavior (Caudron 1993, Waldman 1992). Fournier (1998) expressed the need to reconceptualize consumer resistance and diversify it ranging from avoidance to minimization behaviors to active rebellion (complaining, boycotting and dropping out) (Fournier 1998, p. 89). Others viewed this resistance as a "recursive interplay" (Peñaloza and Price 1993) between the market and the consumer. In Poster's words (1992, p. 1), this interplay indicates a "strategy of appropriation in response to structures of domination". Hence, consumers appropriate the resources of the market as a means to escape the oppressive interests of corporations. Despite these appropriation strategies, corporations still exert influence on consumer meanings, lifestyles and experiences by thriving upon these modes of resistance by the consumer (see Thompson and Arsel 2004 on local appropriation of global brands by consumers and the subsequent appropriation of oppositional meanings created by consumers by the market).

Whether the market objectifies the consumer – as in the Marxian view – or the consumer appropriates market resources for her/his own ends, the consumer is still constituted in an endless pursuit of her/his agency, when in fact there is no real agency. In search of their agency in the market, consumers adopt confrontational means to resolve the tensions between them and the marketers. This issue of the constitution of market actors as distinct and detached entities in a superior/inferior dialectic may essentially stem from the excessive emphasis on objectified constitution of the consumer and subjectified constitution of the marketer and vice versa (Peñaloza and Venkatesh 2006). In addition, contrary to conventional economic theory, Slater and Tonkiss (2001) argue that the market in a broader sense actually represents a variety of mechanisms and institutions that are embedded in a broad range of social and historical contexts. Frameworks that articulated consumer-marketer roles and relations in the market in light of capitalism and its value systems emphasized the issues of whether there is an agency or not, whether the consumer is capable of appropriating the hegemony of the market and escaping the market, and whether the market is capable of appropriating consumer resistance or cooperation.

Consumer researchers' intense focus on structure/agency issues (also evident in Consumer Culture Theory scholars' works) and the use of resistance frameworks in articulating consumer-marketer relations get in the way of understanding why and how consumers are actually participating in the co-production and co-creation processes. Such a focus may cause researchers to miss out the positive and productive aspects of consumer-marketer cooperation, how they build communities of sharing, and how these communities are negotiating the meanings of this cooperation and serving as alternative forms of legitimation. Consumers are not dominated by a singular hegemonic discourse but are governed by and govern through different institutionalizations that produce discourses through which roles, relations, and identities are legitimized and institutionalized (Thompson 2004). The discourses that are generated as a result of certain power relations also encompass consumers and producers. Foucault (1980) argues against the duality of roles and relations (those who have power versus those who have not, oppressed versus oppressor, consumer versus producer) that captures the concept of power, and that no market actor can own or lose, give away or acquire power (see also Shankar, Cherrier and Canniford 2006).

As previously mentioned, in contemporary perspectives, some scholars have constituted the consumer as an agent who tries to emancipate herself/himself from the imposed structures of the market; and this emancipation could only be local and temporal (Kozinets 2002a). Consumers strive to find their liberatory potential through subverting and resisting the market order and escape from it rather than be seduced by it (Fırat and Venkatesh 1995). Consequently, the consumer strives to escape the hegemonic market order and prevail over the dialectical tension between her/him and the marketer. The dialectical tension here refers to the constant struggle of one entity to subsume the other aimed at resolving the conflict between these entities. Therefore, the interaction between market actors ultimately focuses on the resolution of conflictual positions until one entity establishes primacy over the other.

Hardt and Negri's (2000) seminal work 'Empire' provides an alternative conceptualization of bourgeois-proletariat confrontation in the form of empire-multitude. In the Marxian ideology, a type of confrontation occurs between the bourgeoisie and the proletariat, which puts the control and ownership of productive labor in the hands of the bourgeoisie, and assigns the institutionalization of rules of law through structures of the sovereign nation-state. In contrast, Hardt and Negri (2000) suggest that though this confrontation remains, its form is no longer understood in a Hegelian dialectic of contradictions, "a play of absolute negations and subsumption" (p. 189), reconstituting a higher unity. In addition, capitalist exploitation of the productive forces of society transforms into what they call the *Empire,* an imperial rule, which functions as "a *decentered* and *deterritorializing* apparatus of rule that progressively incorporates the entire global realm within its open, expanding frontiers" rather than a rule institutionalized by the nation state (Hart and Negri 2000, p. xii). Hence, Empire's role is to organize and manage hybridity and multiplicity, in their own words "manage hybrid identities, flexible hierarchies, and plural exchanges through modulating networks of command."

Consequently, even though the empire-multitude encounter reflects a confrontational manner, this confrontation is not driven by contradiction or resolved through negation. Confrontation is not constituted in dialectical terms that necessitate the resolution into a higher unity or synthesis (Fillion 2005). As they put forth (Hardt and Negri 2004, p. 208):

> The notion of the multitude based on the production of the common appears to some as new subject of sovereignty, or organized identity akin to the old modern social bodies such as the people, the working class, or the nation. To others, on the contrary, our notion of the multitude, composed as it is of singularities, appears as mere anarchy. Indeed, as long as we remain trapped in the modern framework defined by this alternative – either sovereignty or anarchy – the concept of multitude will be incomprehensible. We need to break free of this old paradigm and recognize a mode of social organization that is not sovereign.

Consumers engage in creative, connective, collaborative, contributive and communal relationships with marketers. Consumers and marketers may hold more salient and conflicting positions that can coexist in particular circumstances. However, these tensions may not necessitate detachment from or resistance to each other, since they recognize each other's differences (may or may not be conflicting). As situations demand, they engage in mutual negotiation and direction of discourses. Such negotiations may enable them to switch their salient cultural positions and adapt them to the expectations of both parties (Oswald 1999), which does not require resolution. As Appadurai (1990, p.226) also proposes, the global consumer culture has the character of a complex, overlapping, disjunctive order that deconstructs the dominant-dominated dialectic. Hence, the perception of consumers and producers in synergistic relations may also prevail, which may not necessarily involve domination of one entity over the other but include constant negotiations between these entities as they both benefit from the market system and discover alternative institutionalizations of organizing lives, with lesser desire to dominate and increased appreciation for difference.

The above mentioned possibilities may also bring new reconfigurations of governing selves and others. For example, in healthcare, physicians are considered as dominating and coercive, and serve as suppressive forces that limit patient capacity to make her/his own decisions (Lupton 1995). In fact, medical paternalism is considered to be the ultimate beneficial provisioning in healthcare (Lim 2002), since it favors the superior physician and inferior patient, who obeys whatever the doctor says and takes it for granted. This excessive reliance on physician's special knowledge and skills generally stems from the patient's belief in the greater ability of the physician to make judgments (e.g., doctors know best attitude), leading to a one-way surveillance and management of patient care by an allegedly superior medical knowledge and rationality (Foucault 1975).

This traditional relationship between the physician – who is the utmost authority and expert gate-keeper in patient care – and the patient – who is obliged to comply with the doctor's orders – (Haug and Lavin 1981) is evolving to a different phase. With the advent of new technologies and the rise of consumerism, the top-down relationship between the patient and the physician, in which the patient was uncritical and non-challenging of the physician's knowledge and expertise, is transformed. The patient has become more critical, assertive, demanding and well equipped with information and experience in a joint relationship with the physician (Edenius and Aberg 2005; Quill and Brody 1996). Patients rely less on the physicians as the sole information source but seek self-help through searching for information online and seeking support from online support groups and other patients who have had similar experiences (Ferguson 2000). The physician-patient encounter is now mediated by negotiations between these parties, the terms of which are determined by the partnership of informed patient and receptive doctor (McGregor 2006). In addition, medical interventions are reconstructed on the basis of changing consumer culture, since patients as consumers make choices based not only on a medical enforcement of curing the disease and maximizing their health but also on a variety of factors that enhance their and others' vitality and quality of life.

Technology and Culture Interplay

Recent advances in communication technologies, that is, the use of social networking and social media for information sharing, collaboration and user-generated content, have remediated the superior-inferior dialectics between the physician and the patient. Consumers' desires for involvement in and control over management of their care have fueled their need for information about their diseases, which is enabled by Internet technologies, and reduced mere reliance on the expert physician (Tyson 2000). In addition, collaboration between patients and their physicians (McGregor 2006) is invigorated by communities formed through social networking technologies. Technology then provides the means for not just self-help but also collective cooperation through online communities and support groups in healthcare, which provide informational, social and emotional support (Burrows et al. 2000; Eysenbach et al. 2004; Ferguson and Frydman 2004; Wright and Bell 2003). Consequently, patients become both consumers and producers of health information and experience (Hardey 2001).

As the roles of consumers and marketers are transformed, consumers become partners with organizations and other market actors in collectivities that are facilitated and empowered by these organizations. Such incidents may challenge the clear segregation between consumers and organizations. In modern market society, organizations are considered as distinct and detached entities from consumers in the market, providing goods and services to satisfy the needs of their target markets (Fırat and Dholakia 2006; Peñaloza and Venkatesh 2006). In the modern marketing organization, the marketing institution was in charge of collecting information about target markets, discovering and providing the needs/wants of consumers. Hence, provisioning in this sequence was performed by the marketer. Yet, as consumers become less and less choice makers from the alternatives provided by organizations and more and more producers and organizers of their own experiences, they increasingly desire to be active players in the creation of offerings by organizations. Consumers are now immediately involved in the discovery processes. Organizations now design the means whereby consumers and other actors gather to engage in joint production. Consequently, organizations serve as a platform for real-time collaboration among market actors, where performers of the market together discover and design their needs.

Fırat and Dholakia (2006, p. 140) also critically approach this segregation and offer to (re)conceptualize the role of marketing: Marketing ceases to serve only as a way of provisioning customer needs, and transforms the hierarchical and linear relations between the consumer and the organization. Marketing comes to serve as an institution of empowering the consumer in constructing communities in and through which s/he is enabled to enhance and reorganize her/his modes of life. Hence, the roles ascribed to consumers begin to entail a constructive or performative mode of consumption, and enable the constitution of the consumer as the "*post-consumer*" through an actual or virtual collectivity (Fırat and Dholakia 1998; Kozinets 2002b).

Changing consumer orientations and value systems also indicate a lessening concern about the acquisition of material values and growing desires to accumulate distinct experiences, navigating one order, then the next (Fırat and Dholakia 2006). These cultural transformations also reflect a distinctly different sensibility than the one that modern culture had cultivated. For example, the impulse to search, find, establish, and diffuse that best order of life seems to be waning in favor of meaningful and distinct life experiences (Lyotard 1984). Furthermore, a 'this *and* that' sensibility is beginning to set in (Fırat 2005) instead of the 'this *or* that' sensibility, which reflected the logic of the culture of modernity that trusted in people's capability of finding *the best* order.

Another issue to be discussed is the perception of co-creation as a form of exploitation. As previously discussed, some scholars conceptualized co-creation as a form of exploitation, possibly due to the fact that they assessed consumer and marketer value systems in material terms. The digital economy fueled by free cultural/technical/affective labor and the resulting materialization of collective intelligence is considered a product of late capitalism (Terranova 2000). The Capital then continues to exercise its power over processes of valorization of this abundant cultural/technical/affective production and exploits and extracts value out of incessant, creative, and updatable collective knowledge produced on the Internet (Terranova 2000). These observations may validate critical school scholars' point that consumers are simply passive dupes exploited by the power wielded through organizations. The capitalist logic may consider virtual collective knowledge production as "free (unwaged and voluntarily given) labor". Nonetheless, participants in this knowledge creation process in communities are generally not compensated according to the capitalist logic, but by exchanges for enjoyment, mutual learning and discovery (Terranova 2000, p. 48), mutual suffering, and mutual prosocial sharing (Belk 2010) of information and experiences.

These complex interactions between the capital and the cultural/affective labor introduce new challenges that necessitate the generation of new orders through which businesses are reorganized, and consumer/organization roles and relations are reconstituted. The impact of technological transformations and changing consumer sensibilities that grew out of disillusionment with modern market society result in productive capacities of a given society to take increasingly immaterial forms (Lazzarato 1996). Those who define value creation in co-creation or exploitation as a result of co-creation within dominant capitalist value systems may need to recognize the emerging value systems that may essentially arise from cultural and technological transformations, and include the non-economic, non-instrumental, and collective aspects of new value systems into their way of thinking. Dominant value systems (framed in the modern economic order and capitalist logic) may then be inadequate to understand the motives (e.g., intrinsic values) that drive individuals to become participants in production processes through new technologies and engage in collective knowledge and experience generation. The implications of such practices (e.g., extrinsic value) on individuals themselves, institutions and the society at large are also important to gain a holistic understanding of the co-creation process.

The rise of the participatory culture with the advent of new communication technologies also introduces issues related to the dynamics of roles and relations in virtual collectivities, the extraction of the social from the market, and the segregation of the consumer from the organization. For example, in this emerging participatory culture, and collaborative experience and knowledge generation, experts are still present. However, they begin to serve as facilitators or enablers, not leaders or rulers in the digital age. In fact, the power of people is derived from creation of excessive fragmentation and miscellany in the digital world (Weinberger 2007). Hence, this miscellaneous collection of anonymous, pseudonymous individuals can perpetuate continuous knowledge and experience generation. Sharing is in fact much more prevalent and encouraged in online platforms than offline platforms (Belk 2010). Through collaborative ownership and collective sharing, members of online communities together can add to knowledge generation in the community, slice and splice it up, reorganize and give it away without losing it (Belk 2007). In fact, capability and ability to give away, deliver and distribute the available resources of knowledge and experience to others, not the possession of these resources, constitutes consumer power, creates value, and maintains relationships in virtual worlds (Hemetsberger 2002). Virtual communities then become s(p)licers of knowledge and experience, and the lives and relationships organized around it.

These transformations may ultimately challenge the modern market order ideals, which promote possessive individualism (Belk 2010), exchange based relations (Bagozzi 1975), and consumer-organization segregation (Fırat and Dholakia 2006). Consequently, we begin to observe the rise of sharing and co-ownership (joint possessions) (Belk 2010), and organization of roles and relations through community level dynamics among market performers. Consumers and marketers are a part of the market system, yet they are also a part of the social and cultural system, presenting their selves as social beings residing in communities (Peñaloza and Venkatesh 2006).

As previously discussed, not just the technological advancements but also changing consumer sensibilities enable such sharing and experience (Davis 2005). Technology is not only a tool but also a constellation of social and human relations within which technology as a tool is just one constituent, "hybrid assemblages of knowledge, instruments, persons, systems of judgment, buildings and spaces" (Rose 1996, p. 26). The growth of wikis and transformation from Web 1.0[7] to Web 2.0 (e.g., social and professional networking sites such as Facebook and LinkedIn) also coincide with cultural changes, where changes along both dimensions foster each other. Recent cultural developments emphasize the turn to experiences and away from material accumulation (Pine and Gilmore 1999), and growing desire to navigate diverse experiences and

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[7] Web 1.0 is described as a "read-only web", in which people only search for information and read it and providers of information have the utmost control over the content (Berners-Lee et al. 2001). Web 2.0, on the other hand, is the second generation of the Internet and allows for interaction among consumers and providers of information as well as users' creative ability to generate online content.

orders of life (Fırat and Dholakia 2006). In addition, trends in consumption practices indicate the growing desire of consumers to become increasingly involved in the co-creation of experiences (Fırat et. al. 1995; Vargo and Lusch 2004). Together, these changes can also evolve the attitudinal and behavioral approaches people have toward life and its meanings. They cultivate a shift in the intellect that promotes sharing and making their private world publicly accessible, blurring the modern distinction between private and public and altering the very meanings of these concepts. Whereas 'private' blurs the distinction between the rights and freedoms of individuals and the rights of private property, 'public' blurs the distinction between state control and control of the common (Hardt and Negri 2004). As Hardt and Negri (2004, p. 204) put forth, the concept of the 'common' cannot be reduced to community or public in network society, and is formed in cooperative social production and communication among singularities in the multitude. These singularities converge in the production of the common, and can get their voices heard through dialogues in a community without having to be melded in the unity of the community. In the post-industrial era, private comes to relate to the "singularity of social subjectivities and not private property, and public relates to the "common, not the state control", through which control is exercised by singularities in a collaborative, biopolitical production (Hardt and Negri 2004, pp. 204-206). Therefore, we observe a shift from 'property' to 'commons', where the former refers to the regulation of one's use of resources by the law, and the latter refers to "particular institutional forms of structuring the right to access, use, and control resources" in a network society (Benkler 2006, p. 60).

Through this mutual interplay between technology and changing consumer value systems and cultural sensibilities, consumers begin to contribute to social and cultural change by turning their participatory experience, knowledge generation and social networking into a business phenomenon together with other market actors in collectivities. For example, in healthcare, patients form collectivities with other patients, doctors, caregivers, researchers, and pharmaceutical companies, and share their experiences and learn from others' experiences on a global scale. Such global sharing of experiences of patients with specific illnesses and the resulting collective knowledge produced from these experiences (e.g., symptoms, treatments received, progress of the disease and treatments) enhance the democratization of patient data. Collaboration on a global scale improves the possibility of new treatments and research efforts, and impacts the course of the healthcare system. With the growing popularity of Web 2.0[8], social networking and social media platforms are now beginning to transform relations among actors in virtual communities, and yielding new possibilities of organizing business that differ from conventional business relations.

Consequently, transformation of social networking into a business phenomenon blurs the segregation between the consumer and the organization in the market and challenges conventional forms of business that treat organizations and consumers as distinct entities that engage in dialectical relationships. Such transformations indicate that organizations do business with the consumer and increasingly partake in construction of consumer experiences as *co-constructors* (Fırat and Dholakia 2006, p. 144), not in a sequential and linear (e.g., gathering of information about consumers to discover their needs and then engaging in exchange relationships through provisioning) but in a real-time discovery process. They engage not in antagonistic (superior/inferior dichotomy) but synergistic and interdependent relations in collectivities.

In light of epochal transformations in modern culture (Featherstone 1991; Lyotard 1984), globalization (Applebaum and Robinson 2005; Ritzer 2007), technology and modern business

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[8] Web 2.0 is considered a technological, social, cultural and even political phenomenon and is coined with terms, such as collective intelligence, architecture of participation, and user-generated content (O'Reilly 2005).

(Fırat and Dholakia 2006), and the resulting multifaceted relations that involve active and cooperative consumer and co-constructor marketer, we need alternative theoretical lenses to explore the dynamics of these relationships. That is, meridian (Cova 2005) frameworks rather than dichotomous frameworks (e.g., dominating/dominated, superior/inferior, resisting/conforming) may further shed light on how consumer lives and their relationships with organizations are reorganized at this point in history. Conceptualizing consumer and organization relations and cooperation in meridian terms mainly requires (1) the abandonment of unidirectional provisioning and overly deterministic actions of marketers – which are prominent in dominant marketing approaches – , and (2) the realization that consumers and marketers are in fact both a part of a social system and a market system. For the supply side of marketing, such "thinking along moderate marketing lines" promotes mutual moderate relations between organizations and all of its actors in society, and involves less consumer takeover of power but more lessening of power exerted by organizations on consumers (Cova 2005, p.210). As Peñaloza (2008, p. 420) also puts forth: "What would marketing and consumer research look like if/when we explode the ontological and epistemological binaries dividing consumers and marketers?" Hence, we need to abandon subject – object distinctions to explore consumer-marketer relations (Peñaloza and Venkatesh 2006). Instead, we need to develop subjective understandings of both actors and their relations. Understanding the dynamics of consumer-marketer relations in a broader social context, rather than extreme emphasis on individual accounts of market actors, may enable the reorganization of business systems that serve as alternative institution(alization)s along with the market order as a macro institution; and emphasize the 'societing' (Cova 2005) aspects of consumer-marketer relations.

Research Context: PatientsLikeMe (PLM)

The decision to research PLM was inspired by the cover story of Business 2.0 magazine. Eric Schonfeld and Chris Morrison (2007), in a cover story titled “The Next Disruptors: The 10 Game Changing Startups Most Likely to Upend Existing Industries and Spawn New Entrepreneurial Opportunities” in Business 2.0, argued that these 10 organizations have the potential to rewrite the rules of existing industries and open up entirely new markets. They also listed PLM as one of the disruptors of existing industries. The following phases of the study then focused on (1) how this organization has developed, (2) how it functions and enables new forms of relationships among actors, and (3) how interactions and discourses among members of PLM community and the resulting institutionalizations make people become a part of these systems.

In 2004, three MIT engineers (the Heywood Brothers), inspired by personal experiences with a life-changing disease (one of the brothers was diagnosed with ALS, AKA Lou Gehrig’s Disease), founded PLM as a privately funded organization. Their idea was to build a community of patients, doctors, caregivers, researchers, and pharmaceuticals that inspires, informs and empowers collectivities. As previously mentioned, PLM is a profit oriented organization that gathers different healthcare market actors on its platform, and transforms social networking (Health 2.0) in healthcare into a business phenomenon. Patients manage their and others’ disease through aggregation and organization of personal health data at no monetary cost. PLM also serves as a co-mediated market platform for collecting and sharing real-world, outcome-based patient data, and real-time partnership among industry actors (data-sharing partnerships with doctors, pharmaceutical and medical device companies, research organizations, and non-profits in pursuit of acceleration of medical research). PLM also uses social networking for real-time research (open and non-blinded, patient-driven and patient generated clinical trials). Hence, the site features various types of relationships – both discursive and substantive – with different healthcare players. PLM also engages in real-time clinical research – which was traditionally the domain of academics and clinicians – with various market actors through sharing and mining of patient experiences.

In the founders' own words, PLM serves as "a new system of medicine by patients for patients". PLM partners with 1) non-profit organizations such as the Accelerated Cure Project and Myelin Repair Foundation, 2) research and academia such as the Forbes-Norris Pacific ALS Centre, Penn State Milton S. Hershey Medical Center, and The School of Library and Information Studies at the University of Wisconsin, and 3) pharmaceutical companies such as Avanir, UCB and Novartis. Despite concerns and skepticism from state agencies and non-profit organizations, pharmaceutical firms such as Novartis partner with PLM and recruit patients for clinical trials through PLM, hence initiating the use of social networking for patient recruitment for clinical research. Kliff (2009), in her article titled "Pharma's Facebook" in NewsWeek, discusses issues related to patient recruitment for clinical trials in medical research and how pharmaceutical firms now increasingly incorporate social networking (Web 2.0) into clinical research, which is considered a novel approach to science and medicine.

The PLM organizational team consists of several teams, the constitution of which is as follows: 1) A management team, which includes co-founders and a marketing and business development founding executive, 2) research and development team, which includes research scientists and a health data integrity manager, 3) technology team, which includes software developers, engineers and architects, senior designers and user interface designers, head user experience engineer, 4) community team, which includes office managers and interns, community managers, and community supporters, and 5) marketing team, which includes a newsletter writer and the marketing manager.

Could PLM Serve as a Potential for Dialogical Constitution of Business Relations?

Ballantyne and Varey (2004), in their critique of the service dominant logic of marketing raise the ground breaking question: Can marketing be really dialogical in the 21st century, since the modern marketing principles and practices, and unidirectional exchanges among market actors dominate societies? They argue that past interactions among market actors were characterized with monological one-way interactions, which have given primacy to the control driven and providing marketers. In contrast, dialogical interactions are based on dialogues among networks of market actors, and are characterized with communicating and acting between – not to – each other (Ballantyne and Varey 2004). Unlike dialectical processes, which require the clashing and resolution of conflicting views at the expense of one party's self-interest and primacy, dialogical processes are founded on *togetherness* among actors in market systems (learning, creating, experiencing together). Dialogical interactions are also released from the past informational (persuasive messages created in hierarchical relations motivated with control and domination) and communicational (inform and listen in interactions and co-produce value) modes of interaction among market actors. Such transformations may deliver the marketing's "unrealized potential of dialogical mode" (Ballantyne and Varey 2004, p. 228), which suggests learning together and co-creating value in learning, and actively engaging in co-determination of value in networked relations despite conflicting or compromising positions.

After two years immersion into PLM, the observations lead to the possibility that PLM may be a permanent example of some changes in market dynamics and exhibit the potential for dialogical orientations and novel organizations of roles and relations among healthcare market actors. There are, it seems different theoretically informative reasons that attract consumers to partake in such an innovative organization of relations and sustain their continuing interest in these organizations. These relations seem to be qualitatively different from conventional market relations. PLM as an institutional order can also maintain their existence in the healthcare market. It partakes in organization of roles and relations, as well as institutionalization of the codes of conduct among/with healthcare market actors.

This research proceeds to the discovery of these new forms of organizing roles and relationships in PLM. In doing so, attention will be given to the meso level institution(alization)s or legitimation processes that develop and maintain these new forms of interaction, lead people to become a part of these systems and enable their continued participation in sharing their private health data and experiences. More importantly, this study will help better understand the role of individual, meso level and larger institutions and their discourses, and how they mutually and concomitantly legitimize the sharing of private health information and engaging diverse market actors in the production and distribution of medicine through social networking. Exploration of social media induced dialogical relations and interactions among healthcare market actors also aims to profile the community mediated process of private health information sharing and generation as a result of synergistic discourses among actors with an increasing appreciation for difference and tolerance for multiple orders, and decreasing desire to contest, confront and establish supremacy.

CHAPTER III

METHODOLOGY: NETNOGRAPHY

Data Collection

In order to provide a complete sense of the nature of PLM as a system and discover the constituents of dialogical processes in PLM, this study will be an extended netnography of this unique healthcare website. Through netnographic analysis, this research aims to seek answers to the questions of how such a system has developed and is functioning, and the institution(alization)s that make patients and other healthcare market actors become a part of this community organization and share their private health data. Netnography as a qualitative research method has several potential benefits. As Kozinets (2002b, p.61) states, "netnography is ethnography adapted to the study of online communities and cultures.

As a method, netnography is faster, simpler, and less expensive than traditional ethnography, and more naturalistic and unobtrusive than focus groups or interviews." Instead of first having to transcribe it and then interpret it, the data comes directly from what community members actually say. Hence, the data occurs naturally and therefore, is not affected by the researcher who collects the data. Netnography can be conducted in a completely unobtrusive manner, since the contexts in which consumers are observed are not constructed by the researcher (Kozinets 2002b). Researchers utilize public information available in online forums, discussion boards and the like, and observe the communal and naturally occurring interactions among consumers in an online research context free of researcher intrusion (Kozinets 2002b).

Through netnography, capturing the dynamics of an online community and how these dynamics are formed through discourses among community members is possible, since netnography is "an interpretive method devised specifically to investigate the consumer behavior of cultures and communities present on the internet" (Kozinets, 1998, p. 366). The understanding developed as a result of netnographic research is informed by researcher's observations of interactions among community members in the form of textual discourse, which provides culturally and symbolically rich meanings (Sherry and Kozinets 2001).

Netnography's focus is not on the micro (individual) or the macro (social systems) level analysis. Its level of analysis is the meso level relations and interactions among collections of people or groups (Kozinets 2010). This research also focuses on the meso level analysis of dialogues and interactions among PLM community members. The initial unit of analysis for this study is the interactions and dialogues among members in forums [MS and Mood sub-communities], PLM community blog [includes dialogues and interactions of all PLM members] and patients' and PLM administrators' own accounts (member profiles in PLM, members' other accounts, such as their blogs, their videos on YouTube and MySpace pages, PLM founders and administrators' videos on YouTube and other websites). Therefore, following similar studies (Brown et al. 2003; Cova and Pace 2006; Kozinets 2002b) conducted on particular communities (e.g., the Nutella brand community), this study adopts non-participatory netnography (AKA Observational Netnography) (Kozinets 2006), and focuses on the contents of forum posts, blogs, PLM website, and community actors' personal web pages or blogs, all of which can be accessed online. Consequently, data compilation for this research is grounded in the collection of texts posted in several digital platforms. The non-participatory approach takes advantage of the textual nature of online communities, and does not necessitate direct participation in members' dialogues (Cova and Pace 2006). Hence, it allows for greater focus on the interactions among the community members throughout their discourses, and avoids any undesirable outsider effects to the community (Elliott and Jankel-Elliot 2003). The study then captures archival data and fieldnote data [9] in the data collection process (Kozinets 2010). Trustworthiness of the study is ensured through following the steps proposed by Kozinets (2002) in netnographic research. Trustworthiness[10] is an important criterion in qualitative research to assess the credibility of a research study based on the constructivist paradigm, and involves extended immersion, ongoing observation, and triangulation (Denzin and Lincoln 2000).

Since September 2007, extensive time has been spent on learning about the community, members of the community (administrators, founders, researchers, software developers, patients, physicians, caregivers), how the community functions, and how it is organized. The study called for continuous immersion in the PLM community, which involves (1) reading news about PLM, (2) watching a 2006 movie called 'So Much So Fast', which is a story about how PLM was founded, (3) spending a considerable amount of time observing the ongoing discourses and interactions among the community members (patients, administrators of PLM, doctors, caregivers and the like), and (4) observing numerous messages posted by multiple members in different sub-communities as a means to identify the components of the textual discourse most pertinent to the phenomenon under investigation. The Multiple Sclerosis and Mood sub-communities served as a potential source for data collection from the forums, since many

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[9] Archival data refers to the downloaded pre-existing computer mediated communications and interactions among community members, which does not require researcher involvement in the creation of data. Fieldnote data refers to the researcher's inscription of his/her observations of the community, its members and dialogues and interactions among members (Kozinets 2010)

[10] In contrast to positivistic paradigm that uses the word "validity" to assess the legitimacy of the research study, the word "trustworthiness" is preferred by most qualitative researchers (Lincoln and Guba 1985; Wallendorf and Belk 1989)

patients from these sub-communities were talking about privacy, disclosure, and community issues in the forum threads and in the community blog. Hence, these sub-communities addressed the largest number of theoretical issues under investigation.

Considerable attention is given to all exchanges in these sub-communities and the patient-to-patient, patient-to-PLM administrators, researchers and founders, and patient–to-physician/caregiver/researcher interactions to discover community dynamics. Due to the immense number of message posts in the forums of sub-communities, a keyword searching method (words used include disclosure, privacy, openness, transparency, community, secrecy and their derivatives) was used to find message posts and interactions most pertinent to the topic under study. As Kozinets (2002, p. 63) also suggests, PLM is a preferred online community for research for four reasons: (1) The interchange of message posts is quite high and dynamic, (2) the nature and focus of the community is pertinent to the research question, (3) the majority of the members are discrete message posters, and (4) the community offers elaborate and descriptively rich data and a vast array of between-member interactions.

The study adopted triangulation and utilized several sources of data including discourses among community members in the forums of the PLM community (e.g., MS and Mood sub-communities), the community blog in the PLM website, news articles about PLM (e.g., New York Times, Business 2.0, BusinessWeek), textual data from PLM patients in their other web pages (e.g., MySpace, PLM Facebook page, personal web pages or blogs), and visual data from PLM patients and founders’ videos on YouTube and other sites. Hence, a vast array of textual discourse in the form of narratives, excerpts, and notes was downloaded. This is a distinctive advantage of netnography, which is the almost automatic transcription of downloaded forum and blog posts that provide culturally enriched ‘thick description’ (Clifford 1990) and understanding of community members. In addition, the data is developed based on researcher observation notes concerning the community and its members, member interactions, and rich meanings of member discourses (Kozinets 2002b). The data collection process will continue until the point where no more insightful categories of interest and importance are generated.

As is the case in any research involving human subjects, ethical considerations cannot be avoided. That is, researchers may need to inform subjects participating in research and obtain their consent (Kozinets 2002b, 2010). Nonetheless, since this research utilizes non-participatory netnography for data collection, there is no intervention or interaction with members of the community for the purpose of gathering information. In addition, information is recorded in such a way that an individual cannot be identified directly or indirectly. Considerable attention is paid to subjects' privacy, and their personally identifiable information is not disclosed. In fact, member's pseudonyms in discussion forums and blogs are not revealed, as they were given another pseudonym in order to protect their real and pseudo identities (see table 2). In addition, I made sure that verbatim quotes from forums included in the analysis they cannot be accessed through electronic search engines by others. Participant consent is not required, since archival and observational research, and the download of existing posts is exempt from human subject research, and the researcher does not intervene in members' dialogues or interact with them (Kozinets 2010). Therefore, the study stayed within ethical boundaries due to the following reasons: "(1) the behavior being observed is commonly performed in public where it is expected that others can observe the behavior, (2) the behavior is performed in a setting where the anonymity of the person being observed is assured" (Zikmund and Babin 2006, p. 242), (3) data collection and analysis is performed on the existing archival or observational data that is publicly available, and (4) the researcher does not intervene or interact with the members of the community (Kozinets 2010). Consequently, for the reasons stated above, this research qualifies for a human subjects exemption (Kozinets 2010).

Data Analysis and Interpretation

After observations and download (of textual data) over a period of two years, the research proceeded, in a more systematic way, to the coding of the data and grouping the findings from (1) the textual data from discourses among community members in the forums, community blog, and patient profiles, and (2) the textual data from the website, other outside sources, such as patients' personal blogs and web pages, and news articles about PLM. These involved many re-readings of the data, and discovering the main themes relevant to the topic under investigation through iterative analysis. Following the inductive coding schema (open, axial and selective coding) suggested by Glaser and Strauss (1967), this research employed the grounded theory approach to formulate a theory about the phenomena. Open coding includes the identification of key words and phrases used in interactions among community members as well as in members' own accounts throughout the entire textual data. Therefore, it enables the general description of what is happening in the data (Goulding 2000).

Discourses among the members of the community, which address the largest number of theoretical issues, were included in the analysis after careful implementation of coding principles suggested by Glaser and Strauss (1967). Thread posts from forums, specifically the ones that offer rich and descriptive content, are most pertinent to the research questions, and involve participation and interaction of different community members (Kozinets 2002b), were carefully chosen for analysis. Taking into consideration some of the most advised steps for narrative textual analysis (e.g. Coffey and Atkinson; 1996; Kvale 1996; Silverman 2005), the following phases of the analysis involved grouping all the findings from the textual data based on discourses among community members, comparing and contrasting them, hence moving to the conceptual development phase (also known as axial coding or conceptual coding). At this stage, the analysis continued to look for emerging patterns and themes as well as irregularities, splitting them into categories, sub-categories, linking them together when possible and creating meaningful categories of several codes emerged at the open coding phase. This application, also known as constant comparative method, is fundamental to grounded approach and enables identification of concepts (Goulding 2000; Spiggle 1994). In this phase, several issues emerged as critical for thorough analysis of the data: (1) Pay attention not to ignore parts of the data that seemed not to fit any of the categories, (2) avoid making categories, which seems to violate the sensitive interplay between different groupings, (3) leave the categories as sensitive as possible to any deviant cases until these cases could also be included to interpretation (Silverman 2005), and (4) refute assumed relations between phenomena, searching for negative cases, and continuously comparing and contrasting different views (Silverman 2005) from the extant literature. In conclusion, the data analysis and interpretation process carefully submitted to the guidelines provided by Spiggle (1994) for qualitative data analysis, and continued until it reached the point of saturation (Lincoln and Guba 1985). That is, the data analysis and its comparison and contrasting with subsequent data (to account for negative cases) from other resources and the relevant literature continued until a complete examination of the data was ensured and no new evidence emerged from the data (Goulding 2000).

Adopting a hermeneutic framework for interpretation of textual data, the interpretation phase involved the iterative interpretation of consumer meanings in relation to both the community member's sense of personal history and a broader narrative context of historically established cultural meanings (Thompson 1997). Consumer perceptions of their selves and their personal meanings may vary according to the situational contingencies and these contingencies depend on which personalized meanings are salient in a given consumption context (Belk 1975). Furthermore, consumers’ personalized meanings emerge through a dialogical relationship in which salient aspects of their life-world experiences impact the ways they interpret these meanings (Hermans 1996). Hermeneutic approach to interpretation of textual data is holistic in nature, since it allows for discovery and disclosure of mutual or complementary relations between individual level perceptions and shared social meanings. Through iterative interpretation, “initial understandings of the text are informed and often modified as later readings provide a more developed sense of the text's meaning as a whole” (Thompson, Pollio, and Locander 1994, p. 433). Textual data also has the potential for discovery of new and different meanings, meanings that even the researcher is not aware of, and will provide new understandings concerning the phenomena under investigation as a result. Such a process then requires that the interpretation of coded text be performed in a “humanistic-naturalistic” manner (Arnold and Fischer 1994, p. 61). Ultimately, through discovery of emerging themes as a result of iterative interpretation of narrative and textual data from this meso context, this study aims to provide macro understandings of phenomena explored, and articulate the implications of transformations observed in this meso context on the overall market relations.

CHAPTER IV

FINDINGS: HOW HAS PLM DEVELOPED AND IS FUNCTIONING IN THE HEALTHCARE MARKET?

Constituents of New Ways of Organizing Roles and Relations among Healthcare Actors in and through PLM

Observations of how different healthcare market actors communicate[11] and maintain relations with each other in this Medicine 2.0 [12] community organization exhibit potentials for a novel constitution of market roles and relations. As a result of iterative data analysis from a netnographic inquiry of PLM, findings are organized around two core themes: (1) Findings help unravel the constituents of these new ways of organizing roles and relations among healthcare actors in this co-mediated market system, and (2) the themes discovered also help us understand how patients, PLM administrators, and other healthcare actors negotiate the sharing of private health information (meso level legitimation processes that maintain people's interest in the community and their continued participation in sharing and organizing private health data), and

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[11] Attention is given to patient-to-patient, patient-to-organization founders/administrators, and patient-to-physician/caregiver/researcher interactions.

[12] Gunther Eysenbach describes Medicine 2.0 applications as web-based services for healthcare actors including patients, caregivers, patients, healthcare providers and the like. Through the use of Web 2.0 technologies, Medicine 2.0 applications enable "social networking, participation, apomediation, collaboration, and openness within and between these user groups". (Source: http://gunther-eysenbach.blogspot.com/2008/03/medicine-20-congress-website-launched.html). Health 2.0 concept involves the combination of health data with patient experience through the use of communication technologies, and facilitates patient involvement in and responsibility for in their own care (See discussion on Health 2.0 by Bos, Lodewijk, Andy Marsh, Denis Carroll, Sanjeev Gupta, and Mike Rees (2008), "Patient 2.0 Empowerment", SWWS08 Proceedings. Available at: http://www.icmcc.org/pdf/ICMCCSWWS08.pdf)

reinstitutionalize surveillance in the healthcare market. In this chapter, the first core theme will be presented.

Provisioning Diluted: (Re)constitution of the Consumer and the Marketer

The first theme discovered relates to how the act of provisioning is diluted and conventional ways of practicing medicine are beginning to be transformed in healthcare. Observations from this community exhibit potentials for the constitution of consumer and marketer as collaborative subjects, who opt to act jointly rather than individually or in opposition in the dilution of provisioning in healthcare. The dynamics of these new roles and organization of relations are described in detail in the following sections. How PLM co-mediates and interacts with these dynamics will also be articulated.

Roles of the Networked Patient

Experiential expert. Patients actively engage in clinical research in this community and participate in the production and distribution of medical knowledge. Their participation in the provisioning of health together with other healthcare actors involves diverse roles. One of the most important roles they perform is that patients convert their personal experiences to experiential knowledge (Jayanti and Singh 2010) and serve as experiential experts:

> Great to see Goetz in NYTimes refer to people here as "co-practitioners"...I see PLM as doing very well, helping patients and families to pool their own experiences, strengths, insights, creating a very real experiential knowledge database that is quite different from the current "professional knowledge" database. Isn't patients' experiential knowledge more timely, practical, and certainly grounded in the 24/7 reality and challenges our disorders and potential recovery from them? (Pat1, Mood)

> The whole point of PLM is sharing, changing the paradigm of medicine where everything is private, learning from each other and contributing to research into our particular conditions…I've never felt that any of the PLM staff claimed to be an expert on mood disorders. We're the experts. PLM is mining our experiences so that others may benefit (Pat2, Mood).

Forum postings from Pat1 and Pat2 in the Mood community reveal that patients perceive themselves as experiential experts, and that PLM mines patient experience to contribute to a pool of patient experiential knowledge. Pat1 comments on a New York Times article talking about how patients become co-practitioners in PLM. Her/his comments reflect the changes in the healthcare provisioning with the inclusion of patients, who now can offer their real world experiences of coping with diseases for medical research in platforms where they can generate experiential medical knowledge together with other healthcare actors. Her/his comments also reflect that such knowledge has its advantages compared to conventional professional knowledge of physicians due to its practicality and real time characteristics. Patients in PLM read each other's profiles and interpret the graphical representation of another patient's health condition and treatment to find an informed or experienced (those taking the medication or using the treatment) person of whom to ask advice (Frost 2010). In an effort to defend and support what PLM is doing, Pat2 points out the sharing (versus privacy) and mutual learning aspect of PLM, which s/he thinks will transform the ways medicine is practiced and medicinal sharing is performed among healthcare actors. S/he justifies PLM's efforts to mine patient experiences based on the acknowledgment and acceptance by others that patients are in fact the experts. They have the ability to change the dynamics of medical research through sharing their experiences and adding to the new knowledge created as a result, which will be beneficial for others.

Presentational mentor. As patients are enabled to change the dynamics of the expertise system in healthcare by sharing their timely and real-world experiential knowledge in PLM, their dialogues during this sharing reflect presentational forms of interacting and communicating with others. In this mutual learning experience, patients offer recommendations to each other based on their own personal experiences rather than enforcing each other certain ways of living with the disease or living out of the disease. Their mentoring of others rests on presenting their own ways of coping with diseases so others observe and learn from it:

> if it helps, read my profile, my symptoms with the onset. if i can do this, you can too. just be strong. I cannot not even think of a word that describes the "fear". I lost most everything i knew and all abilities…but, i made it through all of that....the newer you are at this and the more you lost, the tougher the struggle…I am making my way though....please, be kind to yourself and give it time (Pat3, MS).

The above excerpt is retrieved from a dialogue among patients, who were commenting on another patient's post asking for advice from others. In Pat3's comments, we observe the implicit form of presenting herself/himself and offering help to the patient who asks for advice. Her/his comments imply that s/he encourages the patient in her/his endeavor to fight with MS by giving examples from her/his life. As Pat3 comments on the other patient's problems related to the disease, s/he talks about her/his own experiences, how s/he has coped with her problems, and guides the patient to her/his profile so s/he can observe and learn from it herself. Pat3 exhibits her/his experiences of how s/he manages the disease without preaching to the other patient on certain ways of coping with the disease. Such an act is also discouraged by the organization administrators.

> In group situations, I lead by example and don't worry about who is following. I think having MS for as long as I have and the fact that I am 'still trucking' otta count for something. There is life with MS, but it is up to them to see it (Pat4, MS).

Pat4, on the other hand, adopts a more explicit form of presenting how s/he mentors others. S/he directly states that her/his guidance of others is based on examples from her/his life. Rather than telling others what to do for fighting with MS, s/he presents her/his own experiences, and shows alternative ways of coping with MS through examples from her/his life. S/he then leaves the decision to learn from these experiences and apply them to their conditions to others' discretion.

In general, community members' actions are results of presentational modes of sharing of experiences, stories, and self-revelations. They do not urge each other to take action or suggest issues that would require them to determine and coordinate actions. Instead, members tend to present their tendencies of thinking and acting, and their experiences with incidents in their lives. They talk about what they've done, how they've coped with and treated their diseases, so others can read and learn from them, which then find allure among other members of the community. Patients engage in a presentational mode of suggesting the potentials and possibilities of including the 'other', in order to seek and create rich and meaningful life experiences. In effect, arguing the 'rationale' of what ought to be done is abandoned, 'telling' others what to do is discouraged, 'exhibiting' what can be done through example is preferred (Fırat and Dholakia 1998). They avoid representing reality to others or suggesting unique solutions to their communities. Instead, they present their experiences, ideas about potentials, feelings about events.

Observations from PLM community organization reveal that the value systems and forms of discourse among diverse healthcare actors in this community transform. Institutionalizations of relations and conduct between consumers and marketers are performed by a community of diverse actors in search for the 'possible' instead of the 'proper'. That is, the order of communicating, sharing, and organizing of private health information is not determined/fixed but constantly negotiated in non-confrontational modes. Patients engage in a *presentational* mode of suggesting the potentials and possibilities of including the 'other', the 'unrepresentable' and the unfamiliar (Caputo 1997), in order to seek and create rich and meaningful life experiences.

These burgeoning cultural orientations have also prompted people to readily adopt new communication technologies that enable linking to communities for envisioning new and enticing modes of living and being.

> What can I say to comfort you? Here's how, in my mind, MS does not mean it's over…While MS may have changed some parts of my body, the core essence of me is still the same. I've developed a much stronger spirit…Added new behaviors and habits to my life to build my wellness…Being dx'ed with MS has dramatically improved my ability to live in the present (vs. living in the past and worrying about the future)… My wish for you is that you choose to do what you can do to live as fully as you are able, in every sense of the word (Pat25, MS).

Pat25's comments on a patient who is asking for information and advice reflect the avoidance of representing reality to others or suggesting unique solutions to the patient. Instead, s/he presents her/his experiences, ideas about potentials, feelings about events as s/he mentors and engages in mutual learning experience.

> I visited Tysabri thread looking for information about that drug, and was disappointed to find that LDN preacher there…I wouldn't need someone telling me this drug was my "only hope". As for "no side effects," I found contrary evidence linked on the new "official" LDN thread! Though I'm convinced by others that Tysabri has benefits, his claims are indefensible and go beyond free speech (Pat47, MS).

The above excerpt from a patient also reflects the tendency to adopt presentational forms of discourse. Pat47 expresses her/his distress about a patient, a 'preacher' in her/his terms. Her/his concern is based on the enforcement of a certain medication as the only way to heal a patient. Patients express their discomfort with others who preach to them in terms of medical advice, since such an act is discouraging especially to the new participants, who are so ready to try anything. For this reason, they could be easily exploited by these preachers, who enforce one way of organizing one's care and healing process, and weed out all other alternative modes of coping with the disease.

> I find medical advice very helpful to be able to hear about other people's experiences with meds. People on the forum are very good about saying "I'm not a doctor, GO TO A DOCTOR" but I would still want to ask about people's personal experiences (Pat48, MS).

> You can ask for people's personal experiences. What's not okay is people who take X drug, find that it works for them and go around declaring X drug is the only choice for everyone…"I took X and had Y experience" is fine. "I took X and you should too!" is not fine (Admin2, admin).

In the dialogue above between Pat48 and PLM administrator, Admin2, Pat48 expresses the usefulness of medical advice coming directly from the horse's mouth, and praises PLM members on the integration of patient experiences with physician expertise. Even in the case of desire to seek medical advice, patients and PLM administrators still advocate the presentational forms of advice in the community, as clearly observed in Admin2's comments.

Patients also desire to create etiquette in the community for data sharing, mainly to seek for scientific support for all the claims for cures made by patients and others and to avoid giving medical advice:

> Information regarding treatments offered as a matter of "fact" should always be followed by a direct "link" to that information…it is VERY irresponsible to go around touting "cures" unless you can provide back-up that shows the information is valid. There are many newbies that are so desperate to try anything! Again, these were suggestions that do not have to be followed (Pat49, MS).
>
> if one says they took treatment X and felt better, I wouldn't be all persuaded by references (which are very difficult to interpret even for a scientist!), but rather by seeing that they had filled in their profile in detail and we could all see a real difference in their outcome measure or symptom severity after taking treatment X…Pat49 offered potential bits of etiquette for the forum might be as a discussion point; not an official rule-list (we're more about principles than commandments!) (Sprt3, Support).

Above is the dialogue between a patient, Pat49, and PLM support staff, Sprt3 (please see appendix for more comments from other patients in this dialogue). Pat49 is willing to create etiquette in the community. Her/his comments reveal that etiquette is sought for in the community in order to prevent patients (specifically newly diagnosed ones) from being exploited by others, who make superficial claims without any scientific validation or evidence. Nonetheless, Sprt3 encourages presentational discourses when actors share their experiences with others in the community. S/he argues that both scientific and anecdotal evidence are important for validating claims. More importantly, patients could show and visually present to others what has worked for them and how they have modified their lives in the midst of their diseases by sharing their information in their profiles, so others can view it for themselves and take action accordingly. Etiquettes of sharing and interacting with others are more aspirational than commanding or enforcing certain ways of communicating and sharing. Yet, etiquettes are referred to the extent that they do not possibly cause missing out on some good information. Different perspectives on treatments and medications are welcomed to the extent that they are presented in a complete manner in patient profiles, which also bring credibility to the patient.

Self and Other Validation: Validation of one's and others' health status through collaborative diagnosis. With the changes in the expertise system in healthcare and the inclusion of patients in healthcare provisioning through PLM, the patient comes to be one of the many experts other patients rely on for medical reference:

> Ellen, we have lots of people on this site that are waiting for a DX. Are you seeing a neuro, or just GP? You need to see a MS specialist. There are lots of tests besides MRI to diagnose MS… Have you had any tests? I'm not trying to intrude on your privacy, just trying to learn a little more so we can try to help you. Hang in there…(Pat5, MS).

In the above patient forum post, Pat5, by offering her/his knowledge and experience about MS, is trying to help a patient, who is unsure of whether her/his conditions lead to the possibility that s/he has MS and asks for information and advice. Pat5 encourages the patient to share more information about the patient's disease symptoms and whether s/he has taken certain tests in order to help the patient to better understand her/his condition and ultimately engage in collaborative diagnosis with her/him.

> I was actually looking for information AND validation in PLM and I FOUND IT. Perhaps it's the REAL REASON I keep sharing MY EXPERIENCE, STRENGTH, AND HOPE through my M.S. REALITY... so that those that come to KNOWING ABOUT THEIR OWN M.S. can feel like they HAVE SOMEWHERE to go besides HOPING TO GOD that their Doctor knows JUST A LITTLE MORE than THEY DO about MS... "WE MAY NOT HAVE IT ALL TOGETHER, BUT TOGETHER WE HAVE IT ALL" (Pat6, MS).

Although Pat5' comments imply that s/he actually serves as a confirmer of another patient's disease status, Pat6's forum post reveals that s/he actually is a patient who is seeking confirmation from other members in the community. In fact, s/he states that seeking validation from other patients with similar conditions is the very reason for her/his continuous sharing and participation in the community. Pat5's comments also imply that the patient role of confirming her/his and others' disease conditions serves as an alternative way of gaining knowledge about one's health and disease. Considering that MS is such a complex and vaguely understood disease, rather than just relying on physician knowledge as a source of information and possible diagnosis, patients seek for validation from other patients who have similar disease conditions and enhance their knowledge and understanding about the disease.

In the case of newly diagnosed patients, one interesting discovery is that as patients validate newly diagnosed patients' conditions in the community and help them diagnose their disease, they strive to instill hope in the community through giving examples of success stories of patients:

> Newly DX patients see me using a wheelchair and assume that their MS Passage will put them in a wheelchair. I have to use restraint in my advocacy, to provide hope in the MS mysteries, clarify repeatedly that MS Research is still ongoing & to get as much info and support concerning decisions about a certain treatment…When the question gets too rough, I defer the question to MS individuals with success stories about their progress in therapy… (Pat7, MS).

Pat7 is a patient who is in the severe stage of MS. Her/his comments on newly diagnosed patients imply that validation of newly diagnosed patients' feelings and disease conditions is a subtle role. That is, as newly diagnosed patients observe in other patient's profiles[13] that MS may ultimately confine the patient to a wheelchair, Pat7's strategy of validating their condition involves presenting other patients' success stories and ongoing MS research results to provide

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[13] Each patient profile in PLM shows visually the patient's disease condition and severity of the disease, and many other details about diagnosis, prognosis and treatment stages of the disease.

hope and enable them to make informed decisions about their health. Pat7, as the confirmer of other patients’ health status, engages in presentational forms of sharing her/his experience and knowledge with others (e.g., patient stories, research facts, self-revelations) in order to alleviate the likely fear and lack of knowledge associated with the disease.

Licensed Patient: Patients’ increased feelings of license through social networking in healthcare. Social networking platforms such as PLM enable patients to partake in medical research and the generation of medical knowledge, a domain that used to belong to the influential academics and clinicians in healthcare. In the following dialogue, patients discuss the impact of social networking on healthcare and how it transformed the expertise system in healthcare. Such transformations provide patients with feelings of license to exert control over their and others’ bodies and the physician’s expert power. As will be further articulated in the proceeding sections of the paper, this license is both recognized and approached critically by the influentials in healthcare.

> "TAKE CHARGE OF THEIR OWN CARE”, ULTIMATELY WILL change the nature of drug research and the practice of medicine" -- WHICH IS WHY SO MANY DOCS just CAN'T STAND online stuff... because THEY (not ALL, just SOME) no longer hold THE POWER...because we're entering as EMPOWERED, KNOWLEDGEABLE patients who WILL expect them to have ANSWERS, or at least SUGGESTIONS…It's interesting to watch different medical team members' reactions when I talk about PLM, some are sending their other patients here (AND WHAT an HONOR to be the one to have introduced THEM so that they can pass it on...) but others just sort of roll their eyes and mutter... THESE are the "educators" that I find myself EDUCATING in the end -- the same ones who seem to have the BIGGEST PROBLEM with empowering patients. Quite frustrating at times... (Pat6, MS).

Pat6 comments on a forum thread on the impact of social networking practices on healthcare. The initial tone of voice from her/him concerning her/his engagement in PLM and having a say in determination of patient care reflects the increased feelings of license to exert control over their and others’ bodies and the physician’s expert power. S/he criticizes some conventional physicians’ negative stance toward social networking, and complaints about patient empowerment and increased feelings of license through social networking sites. Nonetheless, the license patients gain does not inhibit the desire to collaborate with physicians in this community. Pat6 actively spreads the word about PLM to other physicians and is proud to see that some of them are inviting their patients to PLM.

> It's about time the world is hearing just how wonderful it is to allow patients to help other patients and let doctors know they really are missing a lot of helpful ideas that can in turn help them help their patients… if they could search PLM and learn something new, they can do more to help their patients, which makes them a better doctor. PLM welcomes everyone and wants us to do our part to help others (Pat8, MS).

In a similar vein, Pat8 expresses her/his hope that physicians could be open to and accepting of patient license and experiential knowledge, and that knowledge gained from PLM could contribute to their expertise. Social networking enables patients and physicians to meet on an equal footing in terms of power relations, and could be beneficial to both parties in their endeavors to help others fight with diseases. Yet, as Pat8's comment also reveals, compared to patients, the conventional medical community tends to be more resistant of patient license to determine the care of patients. Patients still desire to collaborate with physicians on equal terms. In collaboration with physicians and other healthcare actors, patients are willing to complement the physician's expert power with their experiential knowledge. Even though patients may be inclined to resist, this resistance is to reliance on a single source of information and expert opinion, not the expert opinion itself. Hence, patients perceive the physician as one of the many experts they rely on. They want to see the physician as an alternative source of knowledge and expertise in managing their and others' care. Encouraged by PLM administrators, patients do not try to crush the physician's expertise but accept her/his license and experience it, as they perform their roles in helping others for their care. Patients have the alternative to weigh the physician's expert knowledge against the knowledge and experience they accumulate through sharing with others. Moving from a disciplinary society to a control society (Deleuze 1995; Hardt and Negri

2000), the action of control is performed as a shared mechanism among multiple actors. The control of sharing, generation, organization and distribution of private health data is also performed through PLM community actors in healthcare, yet not with the tone of defiance of professional expertise or stand against it in emancipatory or resistive reflections.

Constructive Patient. It is also important to understand the nature of patient license and how such a license becomes a productive force in PLM. As patients perform research together with other healthcare actors in PLM, their involvement in research and organization of sharing of private health data takes on different manifestations. One manifestation of patient constructivism in medical research is that patients engage in research not only by sharing their private health information but also by generating ideas for PLM to use in data generation:

> I pooled all the data we have from the community on the date of possible disease onset, from the diagnosis history…Now that you brought up this question we could include it in a new "community chart" section of the site…What do you think? I'll post a report soon with other charts for your use and entertainment (Res1, PLM researcher)…yes i would love to see the charts, it sure helps. Our own very own research, I like that idea and being part of it…(Pat9, MS).

The above dialogue between Res1 from PLM support staff and Pat9 reflects the integration of patient ideas and suggestions into generation of treatment reports as a result of pooling patient data and how these reports are presented to others. Patients do not just provide their health data and wait for research to be conducted by PLM. They actively engage in designing of research reports and the distribution of new knowledge generated as a result of medical research to others in the community. Pat9’s reaction to these developments reveals that patients live up to the license they gained through social networking in PLM, and that this license enables them to do their own part in medical knowledge production.

> Gail: We designed MS Rating scale in collaboration with an experienced MS specialist…If it is felt there are inaccuracies, we can modify the tool. We did this in ALS community where one member pointed out that ALS rating scale didn't pick up her changes having progressed to a very advanced stage of disability. An extension was designed to pick up on changes (Sprt2, Support).

Sprt2's comment on a patient's forum post (patient shares her/his concerns about the accuracy of MS rating scale after applying it to her/his condition) also reveals that patients actively engage in redesigning of treatment reports or tracking tools with their feed-back incorporated by PLM staff. Sprt2's statement also reflects the changing license structure in the provisioning of health data. That is, although physician expertise is incorporated into the design of the tracking tools, when patients point to gaps in the reliability and validity of such tools, PLM staff makes the necessary changes in the design of these tools accordingly. Consequently, PLM reinforces collaboration en masse by including patient ideas/feed-backs and physician expertise in the design of research and sharing.

> Jan, there is an article about our research with ALS members in Neurology Now. Lithium trial is an example of the power of patients sharing information. After this trial was published, several ALS members decided to try it, and shared their experiences here (including series of videologs from one of our members in Finland), which led to others deciding to try it (Admin1, Admin.).

Similarly, Admin1 (PLM community administrator) articulates patient active engagement in medical research in PLM, how patients track their conditions with surveillance tools in PLM, apply the outcomes of the research to their conditions, and then share their experiences with others. Provisioning of new knowledge and experience created as a result of research conducted in this community is performed by patients through the discovery of new treatments and medications and the distribution of these outcomes to other patients and community actors. Distribution of new knowledge by patients is an ongoing process, since patients who were informed by the results discovered through collaborative research in PLM, apply these results to their conditions and share their experiences with others so that others can learn from them.

Patients and other healthcare actors engage in prosocial sharing and medical research in PLM. Through tracking their and others' diseases and treatments with the surveillance tools, patients increase their awareness and understanding of the disease. They compare their conditions with other patients through this aggregated patient health data. Consequently, they strive to stave off the disease, reduce the suffering associated with the disease, and find a possible cure for life changing diseases. They also aspire to discover unknown side effects of medications[14] and new treatments for diseases, instill collective sense making, learning and understanding of diseases among healthcare actors, and generate and distribute medical knowledge and experience in healthcare.

Another manifestation of patient constructivism is that it goes beyond sharing of private health information and participating in the design of the research process in PLM:

> We are collaborating with Humberto Macedo, a patient, and Karen Felzer, whose father has ALS, to recruit all patients taking lithium. Together, we will run the first real-time, real-world, open and non-blinded, patient-driven trial. We believe we will have the power, within months, to begin answering the question of how much lithium modifies ALS progression (Fdr1, PLM founder).

Fdr1's comments reveal that patients and caregivers actively engage in collaborative research in PLM not only through sharing of medical information but also recruiting other patients for clinical trials conducted in PLM.

Patients also generate ideas for PLM to encourage physician/researcher inclusion in the community as a means to engage in mutual learning experience:

> I'd like to see an actual Neurologists' to answer some of the questions asked to each other on this site…why are Drs so quick to dismiss it when we come to them with symptoms and a POSSIBLE dx?.. it would be helpful to see where Drs are coming from. (Pat100, MS)… Would be nice to have a live chat too, where they could also learn from us (Pat101, MS)…How about once a month quest speaker via forum, from researchers who use the site and actual MS specialist? (Pat10, MS).

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[14] Several patients were already tracking excessive yawning as a symptom on PLM, through our user-added symptom tracker. We have published exciting findings from our community... Another exciting development is first real time drug study (use of Lithium in ALS). Each project demonstrates how PLM community can conduct research quickly and easily to accelerate the pace of gathering and disseminating new knowledge…to better understand the course and characteristics of ALS and to discover and evaluate the effects of new possible treatments (Res1, PLM researcher).

> Combining guest speakers with pat101's idea above we could do an "Ask the Expert" where you all sent in questions, then posted those on the site. We have some work to do on the forum. We'll work on making things easier to figure out… (Admin1, Admin.).

In the above dialogue, three patients from MS community share their ideas about inviting an expert Neurologist and guest speakers (researchers, MS specialist) to the community with PLM administrator, Admin1. Evidently, these patients strive to enhance their connectedness and communication with physicians in the community to support mutual learning, and their ideas are acknowledged and put into process by PLM.

Patient participation and constructivism is not only limited to clinical research, data generation and management, and organization of interaction among actors in the community. Constructivism also involves the negotiation of the script of sharing in the community:

> Forum needs order and leadership…there is information architecture problem…we can no longer find what we're looking for…need to organize topics without suppressing conversation. Someone who is part of the community can take an active role in focusing conversations…I and others tried to do it. But, it is a full time job on a board like this…You also need a way to make knowledge cumulative…gems exist in long threads that get forgotten…classic silo problem...leadership could create the basic structure and provide some oversight. Best way to integrate it would be to automatically hotlink matched words in posts to the wiki/codex (Pat11, MS).
>
> Pat11, you and others are welcome to submit resumes to PLM…we love hearing what you think would improve the site...Your input gets brought into our discussions all the time…when we hash it out and have a timeline, I'll let you know what's coming down the pike (Admin2, Admin.).

In the above dialogue between Pat11, a patient, and Admin2, PLM administrator, Pat11 expresses her/his ideas about the current order and organization of sharing in the community, and suggests that the lack of order and a responsible person for organizing the sharing of health data in forums create chaos in the community. S/he actively negotiates the script of sharing in the community and reorganization of the site to facilitate and encourage sharing of private health data. Interestingly, Admin2's interpretation of this negotiation yields a productive outcome. S/he also encourages patients to be actively involved in the reorganization of the site and turn their capabilities into a productive force as official PLM staff. PLM administrators encourage the negotiation of the script of sharing and design of the site by patients, and the subsequent potential changes in the order of sharing.

Credible Patient. As we observe the characteristics of patient license and how this license helps produce knowledge, organize relations and mentor others when sharing private health data, such a license is also identified with increased patient credibility. Patients collaborate with PLM to aggregate health information shared by patients in patient profiles and forums. Sustainability and healthy functioning of this community organization is dependent on how well patients perform their roles, live up to the license they have achieved, and support continuous sharing of personal health information and participation in clinical research. Patient credibility then becomes an important factor in organizing sharing of private health information and contributing to medical knowledge discovery:

> There is a core number of intense users that generate a lot of our data and information, and those are very important to us, the sort of expert patients or highly engaged patients…there's different types of "expert" patients…those that know a lot about their disease; others that really know about managing day-to-day stuff; those that know a lot about research; those that just provide a lot of emotional support (Fdr1, PLM founder).
>
> I have found this site a comfort in that when others don't believe my invisible MS symptoms ie fatigue, there are many on here who can empathize, it makes me feel sane...ish (Pat12, MS).

In the above excerpt, PLM founder Fdr1 describes the credible patient. S/he elaborates on dimensions of patient credibility, some of which include level of involvement in data generation, and level of expertise (scientific, practical/experiential, and emotional). Credibility of a patient is then constituted through the roles performed by the patient and patient interactions with others in the community, and through PLM administrators' and other members' (helpful remarks) evaluations. Similarly, for Pat12, empathetic sharing and understanding s/he receives from PLM patients is of utmost importance to protect her/his well-being. Patient credibility encourages prosocial sharing among members and is linked to patient expertise that is deemed important in mentoring others about the disease and encouraging them to share their private health data.

> Much of the information sharing and patient-to-patient mentoring happen in forums, but "hard data" sharing happens when you add/update your treatment information. you can then track and manage your condition over time, and it adds to the information in the symptom and treatment reports. People use these reports to learn what others are doing to deal with symptoms, see what's working (or not) (Admin1, admin.)…sharing more information about yourself, symptoms, and treatments may increase your credibility on topics that are important to you (Sprt1, Support).

Other administrators from PLM, Admin1 and Sprt1, highlight the importance of contribution to hard data sharing and maintaining up-to-date information in the database and in patient profiles. This up-to-date and increased sharing of information and knowledge also adds to patient credibility.

> …Three-star patients have provided detailed current and historical information about their condition. Having these complete profiles helps others understand the history and treatment of the condition. Patients earn a star for completing their profile, and keeping their treatments, symptoms, outcomes current…completeness star is for sharing with the community and working with their clinician, to have as accurate a history of the progression of illness as possible…You can also create PLM badge to use in other sites or as a signature on your emails (Admin1, Admin.).
>
> Deep data sharing provides credibility to the patient for all activities on the site (forum posts, private messages, treatment/symptom experience). Every interaction is linked back to patient's profile through "patient icon" that graphically describes patient's current disease status. In essence, sharing data gives patients our version of "street cred" (Fdr2, Co-founding executive).

Specifically, in the above dialogue, administrators assess patient credibility, and employ a star-based incentive program to support this credibility. They assign patients stars that reflect their level of involvement and participation in the community. Patients earn stars based on the amount of sharing they perform with others in the community, amount of detail and completeness (biographical, diagnosis, prognosis, and treatment information) provided in patient profiles, how accurate the data provided is, how up-to-date the information shared is, and how well patients increase connectedness among healthcare actors by inviting others to the community and by collaborating with physicians outside of the community.

> The oceans of mental illness are quite deep and unchartered and I give more credence to the observations and experiences of those who are immersed in it than those who pontifically preach and prey upon it from the shoreline. I checked out a few similar sites prior to discovering this one and somewhat favor the flavor of this one (Pat13, Mood).

For Pat13, those patients who share their lived experiences without preaching others gain more credibility than others who stand aloof and only enforce others on certain ways of coping with diseases. Presentational forms of sharing also enable patients to gain more credibility, hence increase the quality of sharing among members.

Members view each other as a credible resource to inform treatment decisions and contribute to their own decisions along with the consultation of healthcare providers. Patients recommend treatments each other based on their personal experience with taking a drug or using a device. Nonetheless, these recommendations go beyond personal experience, and involve the research patients conduct and the knowledge they offer on relevant research studies conducted on a specific disease. Observations from this community also reveal that patient credibility is judged by other patients through helpful remarks, which are linked to patient profiles. The quality and intensity of sharing are evaluated based on how well others learn from the patient's contribution and mentoring. Consequently, the feelings of license by patients also help exercise control over other patients' bodies, not just the physician expertise.

In summary, the constituents of patient credibility in PLM are as follow:

1. Connectedness (how many people patients invite to group and how well they work with their outside physicians)
2. Contribution (Sharing):

    a. Quality of sharing: Accurate data supported with evidence, supportive sharing (emotional (empathetic not sympathetic), social and scientific support), presentational sharing
    b. Intensity of sharing
        i. Amount of detail in sharing (forum posts, private messages, treatment and symptom experience, etc.)
        ii. Amount of theoretical/scientific knowledge shared about the disease
        iii. Amount of practical/experiential knowledge shared about the disease
    c. Frequency of sharing
3. Community: How helpful patient contributions were found by others (helpful remarks by others, which are shown on patient profiles), how well patients spread the word about PLM
4. Recency (current info): How well patients update their data
5. Completeness: How complete patient data or profile is

Marketer Roles. The marketer in the business order constructed by PLM is constituted as a real-time partner, and a co-analyst of medical knowledge and experience. Patients begin to consider the physician less as a pure authority figure, who tells them what to do. Rather, the physician serves as an analyst, who integrates her/his knowledge and skills with the knowledge and experience of patients. The physician, who comes to serves as a co-analyst of medical knowledge and experience, helps patients contextualize their disease experiences, and constructs alternative modes of managing care with them:

Co-analyst Physician

> In the past, we physicians had information power and (since it dictated our livelihood) we guarded it jealously. Patients didn't have the ability (or desire) to read through complex medical texts to understand their diagnoses. Now, they routinely come to me armed with a printout from WebMd or PLM and more

> often than not they are spot on. As a physician, I am no longer one who hoards information but a consultant who provides experience, context, meaning and perspective to what the patient is experiencing (Phy1, Physician).

In the above excerpt, one of the physicians in the community, Phy1, describes his new role as a result of transformations in new communication technologies that equip patients with the necessary means to become active in management of their care. This physician's argument reveals that with the changing dynamics of the expertise system in healthcare enabled by new technologies, patients become more literate in terms of their diseases, which challenges physician expertise and causes physicians to become conscious of their existence and their roles in healthcare. These changes evidently challenge the physician to reorganize and modify their roles and relations to the patient. The new role involves not the one-way provisioning of information to the patient but working with the patient to provide meaning and context to the diseases. In addition, as patients are equipped with the knowledge and experience gained from social networking sites, they also challenge physicians to become more open about diseases and treatment options.

> Internet has leveled the playing field between expert and novice (doctor and patient). While some doctors may find that challenge threatening to their status as an expert, the Web is now providing the kind of information doctors need to be aware of if we want to continue to be good at our job. If patients consult information online prior to a visit, they can better share in the decision-making process with their doctor. Then, they can go online to find information that reinforces their decision or introduces them to viable alternatives. Doctors should make it a standard practice to recommend accurate, high-quality health sites to each patient. Besides reducing the randomness of a Web search, this can reinforce a physician's advice during a visit (Phy2, Physician).

Phy2 explains the impact of new technologies on the expertise system in healthcare. Her/his comments articulate how this new role of physicians as co-analysts is practiced. Patient increased disease literacy, enabled by the Internet, contributes greatly to shared decision making with the physician. Interestingly, we observe that Internet first and foremost reinforces patients' own decisions about their diseases and treatment options. This process then proceeds to the decision making in the physician's office as they analyze the patient's condition and alternative treatments together. In the process of analyzing disease conditions with patients, internet enabled patient proactiveness also reinforces physician's comments on the patient's disease.

> …I've found both valuable and ridiculous information related to MS on the web. Over the years, I've learned which sources to trust…I learn as much as I can about MS, so I can ask the right questions and help in making decisions with my neurologist. We are a team, I wouldn't want it any other way. He brings years of medical expertise and I bring my own patient perspective so that we can make decisions together…Expert advice from a doctor is absolutely necessary (Pat14, MS).
>
> Good to hear that a lot of us have made changes to our care when we haven't liked our treatment…medicine is a business and hopefully we can take our business elsewhere when we need to cultivate partnerships with doctors… I wish there was a structured mechanism to tell doctors when they had lost business and therefore when they need to update their methods. We have to work up to that (Res1, PLM researcher).

In the above dialogue, Pat14 talks about his experiences with physicians, and argues that internet enabled shared decision-making with physicians is a necessary condition for proactive and complementary relations with them. That being said, the patient treats her/his physician's expert knowledge as a checkpoint through which s/he can confirm the quality of data he collected on the Internet about her/his disease. In addition, PLM researcher Res1 emphasizes the importance of shared-decision making in healthcare to cultivate partnerships with physicians. Through social networking, patients also serve as a checkpoint for physicians to improve on their relations with their patients.

> I am pleased to try to answer simple questions about research and treatment of MS and its symptoms. I do not log on to the site daily, so I cannot answer immediately and can give only general advice and treatment guidelines. I am pleased to post on PLM, as sharing knowledge and experience may make living with MS a little easier (Phy5, Physician).
>
> Phy5... Do you have female MS patients struggling with increased symptoms during their menstruation?..It has been a topic in our forum but I thought I'd get your perspective on it... I see my Neurologist soon and will definitely bring it up. Hopefully he can give me some suggestions. Thank you very much for your time and participation here! (Pat15, MS).

As observed in the above dialogue between a physician and a patient in PLM, Phy5's participation in the community involves sharing her/his professional expertise with patients and helping them cope with diseases. Her/his guidance of patients is not about forcing patients to adopt certain treatments but offering general advice that can be checked and compared with different sources of knowledge and experience. Following Phy5's profile information, Pat15 asks for her/his opinion on a certain topic, which s/he will further discuss with her own physician. There occurs constant comparison, checking, and validation of knowledge gained from others with alternative sources. Patients consider physician knowledge and advice as one of the many checkpoints, through which they confirm their own medical knowledge.

> Those experiencing withdrawal symptoms may visit paxilprogress.org…After reading many case histories on paxil progress, you can judge for yourself if research information Phy4 (a physician) posted is just wishful thinking from the medical profession, which is deep denial about the severity of antidepressant withdrawal syndrome (Pat16, Mood).

The above comment from Pat16 also substantiates the validation of medical knowledge with several sources, and physician knowledge offered in the community comes to be one of the points of reference when patients make decisions about their health. Patients in the community do not readily accept the information shared with them by physicians. They turn to other sites of information and research to further analyze and confirm what physicians have to say about their diseases and treatments.

> Hi Doctor. It is great to see you on board. I've searched through all patients listed in the program who have extreme fatigue. Most state Provigil. I tried Provigil and every energy vitamin imaginable, nothing seems to help me…I know you can't diagnose, but do you have general ideas for these symptoms that I might be able to pass on to my neurologist?..(Pat17, MS).

Pat17's statement reveals that patients do not expect to be diagnosed by the physician but seek general information or expert knowledge from them, which parallels Phy5's perceptions (see previous excerpts above) of her/his role in the community. Pat17 analyzes her/his situation with a physician in the community as a means to seek general knowledge from her/him. Such sharing of information also stimulates discussion and further analysis of the patient’s disease conditions and treatments with her/his physician outside of the community.

Credible Physician/Researcher. Just as with patient credibility, physician/researcher credibility is also important when patients build relationships with physicians in the community and share their private health information with them. Physician credibility and acceptance is intensified when they reveal more information about themselves, have strong professional experience, become more involved with the members in the community, commit to patient care, and substantiate their expert knowledge with relevant research sources:

> Thank you for accepting to work with me Phy5! You have an exceptional history and I'm very impressed by what you have accomplished. brave!..Thank you so much for taking the time to CARE about us, I admire that you come here and work with us (Pat19, MS).

Pat19 invites a physician to be a part of her/his care team in PLM. In doing so, her/his revelations reflect the recognition and appreciation of this physician’s professional expertise and commitment to patient care, which help forge a long term relationship and collaborative work between these parties.

> Hello Phy3, we would love you to join in on the forum (if possible). There are many issues that come up for which your expertise would be most welcome…I hope you will find what you're looking for here also. Join in and feel welcome (Pat18, MS).

Pat18’s comments reveal that physician/researcher interactions with patients generally involve knowledge sharing in the community. Patients also expect that physicians go beyond simply answering patients’ questions but also offer their advice and expertise, and collaborate with patients in the forums, which contribute to their credibility in the community.

> Paxil and Effexor are known to be more likely to cause antidepressant discontinuation syndrome…Tapering off the Prozac is rarely a problem. This option must be discussed with your doctor/ psychiatrist. Scientific citation for this report is: Schatzberg et al. Antidepressant discontinuation syndrome: consensus panel recommendations for clinical management and additional research. J Clin Psychiatry. 2006(Phy4, physician)…Thank you for posting that. It is really nice to have someone who can speak with authority on the subject and add a professional answer (Pat20, Mood).

In the above dialogue between a Mood community patient, Pat20, and a physician, Phy4, the physician reinforces her/his perspective on different types of drugs used to treat depression and their side effects with scientific facts. When physicians/researchers share their medical knowledge with others and are willing to learn from others' experiences, they support this knowledge with research facts, and provide links to alternative therapies for diseases and their research papers (please see more excerpts from physicians on this issue in the appendix).

As previously mentioned, physician commitment to patient care is an important determinant of her/his credibility. Such commitment also helps the physician to forge proactive relationships with patients, encourage sharing of private health information, and contribute to research in the community:

> after the death of my father and serving three years in AmeriCorps I decided to become a doctor. I learned while serving that some doctors were so over booked that they lacked that good one-on-one care. I decided to never be that doctor. if there is something that you would like to ask me, I'll help you out to the best of my ability, if I can't, I'll point you to someone who can (Phy7, physician profile)…Bethany, thank for you help. It's so nice to know that someone with the knowledge that you have really does care (Pat21, MS).
>
> I started working as a psychologist in a large MS center in the Bronx in 1979. Back then we did not have much to offer in terms of drug treatments… After doing research and clinical work for many years, I joined the National Multiple Sclerosis Society in 1997 where I continue to focus on quality of life and quality of care issues (Phy3, Physician).

The above excerpts are retrieved from physician profiles in PLM. These physicians express their commitment to patient care and explain that their commitment revolves around their professional and personal experiences, which are recognized by patients in the community. Physicians and researchers, who are a part of PLM and collaborate with patients in PLM, are also a part of several professional disease-oriented organizations.

Credibility of the physician/researcher also depends on the amount of information s/he reveals about herself/himself. If researchers who try to collect information from members reveal little information in their profiles, some community actors are alarmed and avoid interaction and sharing with them, and police the community by notifying administrators:

> Having difficulty talking to the doctor about walking issues? (Res2, Researcher).
>
> I've just sent an email to the administrator that this person is seeking information from members... Please think carefully before you post on this thread (Pat22, MS).
>
> We ask that researchers fill in their bio, indicating where they do research and what their research interest is. it would be in their interest, and everyone's to tell the community something about herself in her bio. Same thing goes for any user, really (Sprt1, Support).

The above dialogue occurs among a researcher (Res2), a patient (Pat22), and PLM support staff. Res2 has no information revealed in her/his profile. When s/he tries to ask questions to the patients in the forum, one of the patients, after checking this researcher's profile, requests help from the administrator to police such actions and prevent members from being exploited by others. Observations from physician-to-patient interactions also reveal that patients, after reading physician profiles, validate the accuracy of information revealed on other internet sites. Consequently, patients confirm physician credibility based on the amount of the information revealed by physicians and the accuracy of that information, which they check through other sources of information and then decide to share and interact with them.

Another aspect of physician credibility is that some of the physicians/researchers become involved in patient care due to their desire to engage in the hedonic aspects of their profession, and the shift in their focus from information science to health care reform and from maximization of health to quality of life:

> Click here to visit my publications page. Personal experiences with ill family members caused me to shift focus from information science to health care reform. Our sickness care system is badly unbalanced; economic goals replaced care, creating competitive opportunity for the present sickness provider system...An open and shared mind is the most powerful instrument in the world (Res3, Researcher).
>
> I am interested in disease management and review the implications of PLM from a population-based care POV on the disease management care blog. Whether you guys realize it or not, you've taken "open sourcing" and "translational research" to a whole new level (Phy6, Physician).

Res3 emphasizes the broken healthcare system due to replacement of patient care with economic goals, and advocates the openness and shared learning PLM has initiated in healthcare. Her/his perspectives on patient care have changed based on her/his witnessing the long-overdue shift in emphasis from scientific evidence based medicine[15] to experience-based medicine, in which the patient is an active participant and the licenser. Enabled by these transformations, new developments in healthcare provisioning (production and distribution of medical knowledge) lead to increased emphasis on patient care and quality of life issues as well as sharing and openness by its actors, as also observed in Phy6's comments. These changed perspectives reflect the societing (Cova 2005) aspects of healthcare market roles and relations, and the increased subjective understandings of both patients and physicians (Peñaloza and Venkatesh 2006).

In summary, physician/researcher credibility is an important factor for building proactive and complementary relations with patients and establishing trust to encourage sharing by the patient. As observed in the dialogues above, the constituents of Physician/Researcher Credibility in PLM are as follow:

1. Intensity of involvement in the community (e.g., interactions in forums)
2. Completeness: The more information they reveal about themselves in their profiles, the more credible they are perceived.
3. Expertise: (e.g., Strong professional background, amount of research and publication)
4. Commitment to patient CARE:
    a. Interested in quality of life and care issues

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[15] Scientific modern medicine is considered an entity, which enforces regulations that govern conventional medical therapy through evidence-based discourse (Avorn 2000).

    b. Advocates of patient care: members of professional associations with a focus on diseases.
    c. Shift in their emphasis from scientific to hedonic aspects of being a physician, and from maximization of health to quality of life
    d. Advocates of openness and shared learning.
5. Receptiveness to patient proactiveness in her/his care and shared decision-making, and to being complementary to patient experiential knowledge
6. Intensity of sharing:
    a. share their research facts,
    b. provide links to alternative therapies for diseases and their research papers

PLM Medicine 2.0 Community Organization in between Healthcare Actors. As previously mentioned, the PLM community organization gathers different healthcare market actors in its platform, and serves as a co-mediated market system and a social media platform for sharing, organization, production, and distribution of private health data. Different healthcare market actors collaborate for research, seek both emotional and knowledge support, and increase their disease literacy and connectedness to each other through sharing in and through PLM. Inter-disciplinary team of researchers, designers, and engineers in PLM create a platform for patients to both share and use health data, and enable them to integrate their experiences into their health decision making and improve outcomes. Tools are designed to engage patients to record, reason with and apply data to inform all types of medical decisions. PLM mobilizes diverse market actors as a non-state institution through non-dominating discourses (Rose 2007) to achieve prosocial outcomes in healthcare and to cultivate social production of medicine through collaborative medical research and increased sharing of private health data.

> Industry partners utilize anonymous aggregated patient data to further improve their research, and find patients that their treatments provide the most value to in the real world. We want to engage the industry and patients in an effective dialog that can fundamentally affect research, treatments… In doing so, we ask what value engagement with that partner brings to our patient community?..We're engaging physicians through clinical research and conferences and we'd like to see physicians using PLM as a way of tracking patients between visits…(Fdr1, Founder).
>
> With the increasing prevalence of disease all over the world, and the difficulty institutional organizations (pharma, research institutions and government) have in developing viable treatments, providing a platform for patients to share their information to help each other and give a directional kick start to the researchers is very much needed (Fdr2, Co-founding executive).

In the above excerpts, PLM founders and administrators describe PLM engagement in organizing healthcare actors' relations, filling in the cracks of the broken healthcare system as a non-state institution, and developing dialogical relations among them. By putting the patient at the center of medical research and disease management, PLM cultivates collaboration among patients, pharmaceutical companies, and physicians/researchers. PLM also desires to create a platform for physicians to actively utilize PLM surveillance tools and improve healthcare outcomes and increasingly engage in the production and management of medicine both inside and outside of the community.

Another rationale for PLM engagement in organizing and mediating relations among healthcare actors is that by engaging patients and other healthcare actors in continuous sharing and medical research in its platform, PLM seeks to contribute to increased disease literacy of patients and healthcare providers with the research results discovered in the community:

> Our findings on yawning brought to light another reason: people were losing friends because of it as they were interpreting frequent yawning as a sign of boredom or rudeness! My interest now is for two things to happen: for patients and healthcare professionals to clarify to patients that it can be a symptom, and for researchers to investigate potential treatments that might target emotional lability and excessive yawning to improve quality of life of our patients (Sprt3, Support).

In the excerpt above, PLM support staff talks about the side effect of a specific medicine discovered as a result of clinical research conducted in the community. Such research results offer potentials for improved learning about diseases and treatments, and prompt further investigation by researchers.

> my quality of life is improved. I take a better drug for pain... Drugs I'm currently on were never offered to me during my six years with MS, due in part to my inability to adequately describe my symptoms, and my doctor's inability to think outside the box from what he defaulted to using…I learned to describe my symptoms better, shared with my doctor other treatments. This is only due to PLM. With a little time, he became more open, and I communicated better. As we shared ins and outs of our daily routines, we made adjustments from what we learned in PLM (Pat23, MS).

Pat23 also describes how PLM has increased her/his disease literacy and the resulting quality of life. As the patient becomes more literate in terms of her/his disease and symptoms through PLM, s/he can better discuss her/his conditions and effectively communicate with her/his physician, which in turn contributes to physician disease literacy. Both parties analyze and integrate the knowledge gained from PLM into their shared decision-making.

Although reliability and validity issues concerning PLM research are raised in the community, both PLM founders and patients emphasize the discovery oriented nature of this research and that their research could be used as a means of validation for randomized clinical trials and draw attention to the hypotheses generated for further testing. Despite skepticism by some influentials in the healthcare market about PLM using social networking and engaging in medical research by various healthcare actors, PLM's research is beginning to gain wider acceptance in the market. As sharing of private health data is legitimized in PLM for the greater good of research and improved and faster health outcomes, the subsequent medical knowledge generated by this community is also recognized by academia (e.g., PLM earned a British Neuropsychiatry Association award) and the healthcare industry. PLM is also recognized for its innovativeness (FierceHealthIT prize) and surveillance tools for patients and other healthcare actors to transform the way medicine is practiced. Such recognition and affirmation is based not only on the scientific contribution PLM makes to healthcare through clinical research and the resulting creation of new scientific knowledge, but also on the social and artistic contribution (e.g., sophisticated surveillance tools) to patient decision making and management of care (please see more excerpts on this issue in the appendix).

Through mediation of relations among healthcare actors and collaborative constitution of roles and relations, PLM aims to increase sharing and connectedness among actors in these networked relations, and support proactive and complementary relations between patients and physicians, not only in the community but also outside of the community. As previously mentioned, there occurs a constant process of confirmation between physicians and patients when they share their medical knowledge and experience:

> When I go to see my Neuro I have papers in my lap and he does his checks and then asks do I have any questions and up comes my list and I go right down it..I listen to his offers and suggestions but I make the final decision. gotta take control of your life (Pat9, MS).

The above excerpt is retrieved from a dialogue on patient proactiveness in forums. Pat9's experience with her/his physician reflects the importance of proactiveness enabled by PLM tracking tools. These tools equip her/him with information, which s/he will further discuss and analyze with her/his physician. Without denying physician suggestions, Pat9's take on proactiveness reveals that such an attitude offers alternatives concerning treatments, from which the patient makes the decision about her/his care.

> I believe it's important to be proactive…at least there are choices for treatments. But how do you know which one is best? You can read everything on the Internet and be proactive, yet still be confused. My neurologist "explained" the differences between Copaxone and Rebif, but left the choice completely up to me (Pat24, MS).

Pat24's perspective on proactiveness also points to the alternatives to choose from. However, whereas Pat9 uses the information learned from PLM to validate the information received from her/his physician, Pat24 perceives the physician as a source of validation to confirm the information collected from Internet sources. Similarly, both patients state that the decision to choose from alternatives is made by the patient, after careful analysis and mutual confirmation from both sides.

> I consider myself proactive in that I take each DR's input as recommendations, then I research to the point where I'm comfortable or not with a decision. After all, it's my body, my life, my wallet…It's great to have a collaborative relationship with your doctors (Pat25, MS).

Pat25's position is similar to that of Pat9, in that her/his proactiveness starts with listening to her/his physician and then validating what s/he has recommended through different sources of knowledge. PLM cultivates collaboration among healthcare actors through supporting proactive and complementary relations with physicians outside of PLM. Patients talk about the importance of being proactive in their management of care, enabled by Internet technologies. Such proactiveness helps patients build complementary relations with their physicians as they further analyze their situation with physicians and integrate physician recommendations in their decision making about their health:

> Knowledge is good…information and communication are equally important, not just with our neurologist but if you have several doctors like me, make sure they communicate with each other. I know that we can convey information ourselves but sign that form so that they are able to discuss all aspects of our health directly to keep confusion of medications/treatments at a minimum. Every decision regarding your health should be yours in the end but listen with an open mind to your doctor; even a bad one will say something of value from time to time (Pat26, MS).

Pat26 stresses the communicative benefits of patient proactiveness. Her/his comments reveal that patient proactiveness coupled with openness is important both for knowledge gain for patients and improving communicative relations *with and among* physicians in healthcare. In doing so, complementarity prevails over conflict in relations with other healthcare market actors.

How has PLM developed and is functioning in the healthcare market?

[Insert Figure 1 and Figure 2 about here]

Observations from PLM help articulate how new forms of business roles and relations are beginning to be formed today in light of technological advances and changes in consumer-marketer discourses, institutional roles and value systems. The above findings help us understand how roles and relations are constituted and organized in the healthcare market with the inclusion of PLM serving as a co-mediated market system and enabling the dilution of provisioning in healthcare. The inclusion of PLM in the healthcare market and the resulting social co-production of medicine with diverse healthcare actors in this platform also sheds light on how marketing systems may be changing as a result of these systems utilizing social networking and engaging in reformation/reconstitution in healthcare. In order to articulate the theoretical/conceptual explanations of how business is reorganized by PLM – how and why such a system attracts patients and other healthcare actors and (re)organizes their roles and relationships – Foucauldian notions of biopower and biopolitical production will be revisited.

Biopower

Foucault (1990, p.139-140) first coined the term biopower in *The History of Sexuality* to refer to the emergence of various disciplines or institutions (e.g., universities, secondary schools, barracks), hence the “explosion of numerous diverse techniques for achieving the subjugation of bodies and the control of populations”. In general, biopower, a new modality of power, reflects the nation state’s concerns with prolonging the life of populations and taking control of bodies through regulatory controls (control of populations) and disciplinary techniques (control of the individual body). Technological advancements of the networked society further stimulate surveillance techniques to control populations, thus the excess of biopower (Foucault 2003) in a panoptic gaze. Foucault’s (1990) concept of biopower – a modern disciplinary discourse to exert control over individuals’ lives and optimize and govern bodies – may be considered a tool for Empire to exercise power over forces of social and immaterial production of the multitude (Hardt and Negri 2000). In the Foucauldian notion of power, biopower is not considered a repressive form of power but one that acts on and through individuals’ actions, desires, motives, bodies, and produces relationships by giving them a sense of freedom (Foucault 1980). Thus, biopower incorporates the seamless coalescence of disciplinary techniques for optimizing and managing bodies (Hiley 1984). For example, modern physician-driven medicine as a disciplinary entity has long had the utmost influence on shaping our bodies as a means to maximize health, prevent death, and regiment our subjectivities. State institutions utilized ‘security’ as a discourse of power in this process (Epstein 2006), particularly as a means to establish laws and regulations to protect patient privacy. Discourses of fear and restitution of normality through threat of death were utilized by these entities in order to increase mortality salience among patients, and have them internalize these discourses to discourage them from openly sharing and distributing private health information to third parties. In effect, the top-down approach in medicine has alienated its users (patients and physicians). Consequently, traditional relations between patients and their physicians rested on the one-way transmission of authority to exert control over patient care and responsibility to maximize the health of individual bodies.

Biopolitical production

As new technologies and social networking practices exhibit potentials to change the dynamics of this dominant expertise system in healthcare, patients, once dominated and passive, are beginning to be increasingly involved in their care and challenge the physician’s expert knowledge. Such confrontation with and resistance to physician domination in medicine brought forth patient self-help practices with information and experience sought from and shared with other patients, support groups, and other relevant sources on the Internet. The result was patient generated knowledge and experience. This knowledge and experience production is called biopolitical production, which is the immaterial production of Multitude, and is considered a tool to transform Empire's (the ruler) default position: domination (Fillion 2005). Immaterial labor of Multitude (the ruled) involves "production of ideas, images, knowledges, communication, cooperation, and affective relations that tends to create not the means of social life, but *social life itself*" (Hardt and Negri 2004, p. 146). In this social life, we observe the "increased overlapping of the political, the economic, and the cultural and investment on one another" (Hardt and Negri 2000, p. xiii). Through biopolitical production, individuals 'share' their ideas, ideologies, knowledge, experiences, passions, and move beyond the dominating urges of Empire and embrace the 'shared' world that provides new possibilities of organizing lives**.** Hence, technological advances and transformations in consumer value systems have enabled patients to become productive forces in medicine and actively participate in medical practices through knowledge and experience generation. Hardt and Negri (2000) emphasize the dynamics of the productive capabilities of the multitude, which include creativity, communication and contact. In doing so, they call attention to the dynamics of the biopolitical production or immaterial labor of the multitude and move beyond the dominating and regulatory interests of biopower (Fillion 2005). A new kind of shared and user-driven medicine is on the rise with the increased creative efforts and active engagement of patients in the medical knowledge generation process. Consequently, unidirectional provisioning and overly deterministic practices of healthcare providers and governments in patient care are evolving to a different phase.

Biosociality

Changing power dynamics and the dynamics of the expertise system in healthcare also brought forth the possibilities for patients to partner with their physicians and co-create patient care through the alignment of physician expert knowledge with the patient experience knowledge (aligning evidence-based medicine with experience-based medicine). This alignment is also stimulated by changing cultural dynamics in medicine, such as a shift in the focus from medical enforcement of curing a disease and maximizing health to enhancement of quality of life. From a theoretical vantage point, the initial conceptualization of biopower in opposition to biopolitical production, regardless of the form it takes (e.g., working with and through consumer freedom), involves a dialectical process. Biopower describes the use of patient body as a medium through which the state and healthcare providers perform their regulatory and overly deterministic actions to provide health to the patient unidirectionally. In contrast, biopolitical production describes the liberatory potential of the patient body achieved through patient resistance to the oppression from healthcare providers and state regulations on patient privacy, a process enabled by new technologies. Moving beyond the controlling and dominating aspirations of biopower and the negatory confrontations of biopolitical society[16], healthcare market now encounters the rising participatory and productive capabilities of networked Medicine 2.0 patients, and the new sociocultural, communal, and creative processes of production of medicine in the healthcare system.

Calling attention to the dynamics of the productive capabilities of bipolitical society, we observe in the functioning of PLM that biopolitical production of the networked patient

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[16] Hardt and Negri critically approach this dialectical tension between biopower and biopolitical production, which was evident in the Foucaldian perspective that overlooks “the real dynamics of production in biopolitical society” (Hardt and Negri 2000, p.28).

embodies a collective and synergistic process, in which new forms of collective identification are occurring and governing of relations through communities is made possible. After all, patients, physicians, researchers, and pharmaceutical companies in healthcare are both a part of the healthcare market and a part of the social relations that make up the healthcare market (Cova 2005). The mutual interplay of technological transformations and changing consumer/marketer value systems lead to the conversion of patient participatory actions into a business practice, thereby enabling patient participation to become a productive force. In PLM, patients contribute to the generation of collective medical knowledge and clinical research together with other patients, pharmaceuticals, physicians/researchers, and government. PLM organization creates a community of diverse healthcare actors and challenges the conventional ways of practicing medicine that treat physicians and their patients as alienated and distinct entities that engage in dialectical relationships. Medical experience and knowledge are co-constructed in real-time together with different healthcare actors in PLM.

Rabinow's (1996, p. 102) concept of "biosociality" could describe this process, which puts emphasis on the engagement of individuals in sharing experiences and changing their relations to their families, social and business environment, and their lifestyles. Biosocial collectivities gathered around a shared somatic experience may involve medical activists, who strictly stand against the conventional medical expertise, people who choose to detach themselves from the modern practices of medicine and remain anti-medical, and others who choose the middle ground and wish to complement conventional medical expertise (Rose 2007). Those who choose the middle ground and coexist with the conventional medical experts also engage in new forms of relationships with other experts. Hence, the long reign of contemporary medicine in shaping our corporeality seems to be waning, as patients become more active in management of their care and allow others to have a say in it. Patient corporeal experiences are now (re)constructed by new forms of intervention with other consumers, medical experts, researchers and the like, hence initiating new forms of biosociality. Through innovative social networking practices and mutual surveillance tools comes the birth of biosocial associations in healthcare, and the practice of contemporary medicine is beginning to transform.

Such a new form of biosociality is evident in the development and functioning of PLM. That is, the reorganization of business relations in the healthcare system is also performed by a meso level institution, along with the healthcare market as a macro institution. Additionally, such reorganization puts emphasis on the social and cultural fabric of such an institution. PLM as a co-mediated market system 1) (re)attaches market actors to each other and increases their connectedness and disease literacy in its platform through surveillance tools, 2) reinforces collaboration by including patient ideas/feed-backs and physician expertise in the design of research and sharing, and enabling proactive and complementary relations with healthcare actors in and outside of PLM, and 3) enables a dialogue and learning with among actors in the healthcare system. How is this dialogue constructed in the social co-production of medical knowledge and co-creation of medical experience, and what aspects of technology and value systems contribute to such dialogue?

As articulated in the findings, for the patient, the meaning of expertise is somewhat different than the common perception of expertise in healthcare (e.g., dominance of scientific evidence-based knowledge). The patient becomes the experiential expert, sharing her/his personal experiences and how s/he copes with the disease so others can observe and learn from these experiences. Patient active engagement in clinical research in PLM and the subsequent production and distribution of real-time medical knowledge also change the dynamics of provisioning in healthcare. Interestingly, both the physician and the patient become checkpoints for each other. A constant mutual validation process is occurring in patient-to-physician interactions. Physician professional and theoretical expertise becomes a point of validation for the patient, who tries to confirm the knowledge gained from other sources. Physician expertise is also validated by other sources of information. Patients become sources of validation for each other for collective diagnosis, prognosis and treatment. Patient experiential knowledge becomes a source of validation and a way of increasing disease literacy for the physician for all stages of a disease. Consequently, the physician becomes one of the many experts patients rely on to enhance their quality of life and stave off diseases, and the patient becomes a recognized source to rely on for validation of new medical knowledge for physicians and academic researchers. Patients present each other their experiences of how they cope with diseases, rather than preaching to each other on certain ways of treating the disease (e.g., recommend and insist on certain types of medications to other patients). They instill hope in the community as a result of prosocial sharing of private health information and finding cures for life changing diseases. Evidently, these value systems and forms of discourse, which both patients and physicians adopt and lead to real-time discovery and distribution of medical knowledge, are also a result of changing expert dynamics and license structures in healthcare. It is not surprising that the patient body is no longer an object of one-way surveillance and domination by the superior medical gaze. Social networking has contributed to patients' feelings of license to exert control over their bodies. However, this license has also enabled them to actively participate in clinical research, a domain in which the dominant experts were clinicians and academics, who conducted and validated their research with total control over the research process (e.g., choosing whoever they want to include in research). Such transformation in license structure of patients and physicians in this biosocial community enables the patient to become proactive and complementary to physician knowledge and medicine. The patient becomes constructive in 1) clinical research, 2) reorganization of data sharing and interaction in this community, 3) recruiting other patients for clinical research, 4) generation of ideas to increase physician-patient connectedness, and 5) negotiation of script of sharing in this community. All of this is performed to facilitate and support increased sharing and connectedness in the community and outside of the community (e.g., facilitate physician-to-patient dialogue outside of the community). Consequently, patient license becomes a productive force, not confronting or distancing themselves from physician expertise but embracing it as one of the many alternative sources of knowledge. Such a license, which also serves as a basis for patient credibility, is then assessed by other community actors and administrators in PLM, and is further enabled to increase sharing and mutual learning. When patients become experts, which may have differing levels, their expertise in the community is legitimized by other market actors and administrators to facilitate and encourage sharing of private health information and contributing to science and medicine with the patient-generated clinical trials as a result of prosocial sharing.

The physician/researcher, on the other hand, becomes more receptive and tolerant of shared decision making with patients. Her/his dialogue with the patient rests on the recognition of patient license and integration of her/his theoretical knowledge with the patient’s experiential knowledge in her/his analysis of patient conditions. Despite skepticism by influential physicians or healthcare providers in the market about the validity and reliability of research conducted by a group of patients, physicians, and researchers in PLM, such endeavors gain recognition by these influentials and begin to serve as a checkpoint for traditional clinical trials and academics’ and clinicians’ own research. Additionally, as observed in patient dialogues, patients further research about and confirm the knowledge gained from physicians about their diseases and treatments. Physicians also substantiate the general knowledge shared with the patient with relevant statistical facts or research links in the community, which leads to the possibility of increased connectedness between patients and their physicians outside of the community for further analysis of patient conditions. The value systems physicians adopt in building such a dialogue with patients also lead to increased sharing of private health information between patients and physicians. For example, physicians put more emphasis on quality of life issues, rather than maximization of lifespan, in patient care, and advocate openness and shared learning in healthcare. They recognize patient experiential knowledge and support their professional knowledge with alternative sources of information to be accepted and relied on by the patient. They are increasingly committed to patient care – stimulated by their personal and professional experiences – and proactive and creative relations in user-generated healthcare. Their focus shifts from mere reliance on scientific evidence-based medicine to hedonic experience-based medicine. After all, medicine is not only about making the patient better or extinguishing the disease through scientifically plausible treatments but also about understanding and analyzing how the patient experiences the disease and is affected by it. These value systems also contribute to physician credibility in the community, build proactive and complementary dialogues between patients and physicians, and encourage sharing of private health data.

By mediating these networked relations and enabling collaborative reorganization of roles among healthcare actors, PLM cultivates connectedness and productive communicative relations, and institutionalizes possible codes of conduct among healthcare actors through complementarity and proactiveness in and outside of the community. From a theoretical vantage point, this mediation is akin to the task of a contemporary pastor. A contemporary pastor enables different healthcare actors to embrace each other and to experiment, experience, share, and interact with other performers to form new associations (Rabinow 1996). Besides, this anecdotal experience sharing is mined with sophisticated surveillance tools and turned into data to generate new medical knowledge. The result is faster discovery of treatments or cures for diseases, increased disease literacy for both patients and physicians, and real-time mutual surveillance of disease conditions and patient care. In Foucault's terms, pastoral power is a system of power relations, which is a form of collectivizing and individualizing power concerned with the welfare of the "flock" as a whole, yet contemporary pastoral power does not depend on organization or administration by the state, which was the case in Foucault's work (Rose 2007, p.73). Hence, other institutionalization mechanisms also structure actions and capacities of individuals. Governing of the flock in this process may be performed by guiding actions of *free* subjects but always in light of the likelihood that the subject can navigate or negotiate these actions in new and creative ways. Also, pastoral power is considered one of the first revised notions of power in Foucault's later work, which expresses that "power is not always exercised in agonistic force relations but can also function through structuration of subjectivity through various non-dominating tools and techniques" (Hartmann 2003, p. 7).

PLM as a contemporary pastor bases its pastorship on relational (Rose 2007) and sociocultural aspects of business organization, and involves affective, bidirectional, and presentational interactions centered on dialogue (or quatrologue, now that pharma, patient, physician, government connectedness is intensified with PLM, thereby introducing new associations in healthcare). In this interaction among performers of the market system and pastoral experts in between, our corporeal existence, which is central to our hopes, subjectivities, collectivities and biological citizenship (Rose 2007), is beginning to be s(p)liced up, (re)deconstructed by others and by ourselves with the discourses of optimization of lifestyle rather than lifespan, hope rather than fear or mortality, and collaboration rather than domination/sovereignty or resistance. Furthermore, as pastors mediate these relationships, they blur the boundaries of coercion and consent through non-dominating regimes such as quality of life, and cultural values such as voluntarism, transparency or openness.

Foucault (2003, p. 126-127) elaborates on the characteristics of pastoral power in his work titled *Security, Territory, Population*. He suggests that the shepherd (pastor) does not exercise her/his power over “a unity of a territory” but over a flock, over a “multiplicity on the move”, and the form it takes is not about claiming superiority. Another feature that defines this type of power is that pastoral power is fundamentally about both individual and collective caring of the flock, “a power of care” and “beneficence” and an “art of governing men” (p.166). This beneficence of the shepherd is about keeping the flock in his constant watch for any possible damage from outside and is about selflessness. Serving the flock and serving as the intermediary between the flock and the pasture (the end) is the ultimate function of the shepherd. Yet, there may be bad shepherds who only think of their own profits and also good shepherds who solely think of their flock, and there can only be a single shepherd with several different functions for a flock. The contemporary society now encounters several experts that may be likened to pastors (not a single pastor for a flock but a community of pastoral experts); yet also witnesses reorganization and modification of pastoral functions and modalities. Contemporary pastorate is about serving as a mediator, yet not separate from those whose relations are organized by the pastor. This pastor actively engages in institutionalization of roles and relationships in the flock and seeks to balance the nature of beneficence (neither selflessness nor selfishness).

The emergence of biological citizenship is beginning to reorganize duties and expectations of individuals in relation to their sickness and life as well as their relationships with others, such as their physicians and other experts (Rose 2007). As individuals become more involved and active in management of their health, we also encounter the emergence of new pastoral experts (e.g., genetic counselors) other than physicians in healthcare to advise and guide them and provide support (Rose 2007). Hence, what we termed as medicine is now becoming a shared field of experience, which dilutes the sole authority and provisioning of the medical doctor and brings a complex division and reconstruction of labor in healthcare as well as a constellation of new forms of practices and discourses concerning consumer health.

In addition, the practice of medicine in disciplinary society focused on normalization of the body. As also mentioned by one of the PLM patients, most healthcare providers are overly focused on preventing physical disabilities, which causes them to lose their focus on quality of life issues. Cole (1993, p. 15) touches on this extreme focus on normalization of body by referencing Foucault that individual bodies are "normalized in an endless elaborate surveillance (e.g., through medical and psychological examinations) in the form of measurement and standardization". In the same vein, Foucault also argues that the segregation of the normal and the pathological manifests itself through production of deviance and threat located in the body, which then produces and stabilizes the norm. The practice of medicine today comes to be less about restitution of normality (normal body, healthy body) to compensate for diseases but more about enhancement of corporeal existence and quality of life through construction of social networking communities with both scientific and experiential experts.

Consequently, as articulated in the dynamics of these new forms of roles and relations in PLM, the way business is reorganized today in healthcare is changing through social networking applications. Nation state and influentials in the healthcare market were the sole legitimate locus of determination of health and sharing of private health information (e.g., HIPAA regulations). Clinicians and academics exerted total control over the domain of medical research and practices, and served as the provider of health and well-being for patients. These experts' disciplinary practices sought to enforce certain ways of being and acting on patients to gain a normal, healthy body, and prolonged lifespan.

With social networking practices and social media platforms in healthcare, the ruling power of these experts begin to diminish as a result of increased feelings of license by patients. Patients use technologies to become active players in healthcare and have a say in determination and practices of health. As patients engage in biopolitical production of medical knowledge today as a result of active involvement in clinical research in PLM, their motives and desires manifest into collaborative and embracing practices rather than sovereign or emancipatory practices. PLM becomes a community platform for cultivating co-creation of medical knowledge among diverse healthcare actors including patients, reconnects the patient to different healthcare experts in this biosocial platform, and maintains a balance between experience-based medicine and scientific evidence-based medicine. How the dynamics of this cultivation are energizing dialogical relations among healthcare actors and keeping them in the community is also an important matter of inquiry to discover the why and how of engagement in research and continuous sharing of private health information by PLM community actors. The second theme of this research focuses on the meso level legitimation processes of sharing of private health information that maintain community actors' continuous participation in sharing and organizing private health data, and the reinstitutionalization of surveillance in the healthcare market through

PLM. In doing so, the seeming tensions occurring among community members in the processes of sharing health data and conducting research will also be presented.

CHAPTER V

FINDINGS: FORMS OF SHARING THAT LEGITIMIZE THE ‘SHARING’ OF PRIVATE HEALTH DATA IN PLM

Sharing versus Privacy?

Forms of sharing in PLM

[Insert Figure 3 about here]

The second core theme discovered helps us understand the dynamics of how healthcare actors relate to each other and keep sharing their private health information in the business order constructed in and through PLM. Specifically, attention will be given to the institutionalizations of sharing in this community. Discovering why and how healthcare actors engage in social co-production of medical knowledge and continuous sharing of private health data in PLM will also help articulate the synergies occurring in the decisions to practice sharing versus privacy. This chapter focuses on the forms of sharing enabled by PLM, which keep community actors share their private health data in the community and enable new forms of organizing the production and distribution of medical information and knowledge in healthcare.

i. From anecdotal to structured and centralized sharing for decentralized decision making in healthcare. PLM brings a structural approach to sharing private health information, which is an important factor for patient involvement in sharing in this community. Stories, narratives, anecdotal sharing of experiences are turned into systematic, structural sharing for research conducted by a community of patients and other healthcare actors brought together in this platform. This is a sharp distinction from online health information sites, such as WebMD, DailyStrength, RevolutionHealth, Organized Wisdom, Sermo (physician community to exchange information), which serve as providers of online health information and platforms for sharing medical information at the anecdotal level.

PLM is open to everyone (patient's family members and friends, caregivers, researchers, pharmaceuticals and the like), not just limited to physicians or patients. Patients quantify their personal health information, turn it into hard data, and track each other's disease conditions through sophisticated surveillance tools on the website. They keep journals of their own individual experiences. They list symptoms of the disease, treatments received, and different lifestyles led. This individual patient information is pooled for research, systematically recorded for analysis and visualized with graphs. Hence, patient experiences and data are pulled together in a way that allows both the individual and the comprehensive view of the disease. Actors in the community interact with each other anecdotally through private messaging and/or public messaging in forums and the website's general community blog. They create profiles and share their experiences in forums and community blogs. Both forum interactions and profile data are used for medical research. Although, the organization encourages public profiles, patients have the option to either make their profiles visible only to community actors or to general public[17]. Structured and centralized sharing is one of the important factors that maintains patient interest and sharing in this community:

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[17] As of May 9, 2010, PLM has 8410 profiles that are public. 56436 members share their profiles only with PLM community.

- MS community – 2609 public profiles, 16450 profiles only visible to PLM MS community
- ALS community – 846 public profiles, 3671 profiles only visible to PLM ALS community
- Mood community – 1695 public profiles, 13978 profiles only visible to PLM Mood community
- HIV community – 386 public profiles, 2315 profiles only visible to PLM HIV community
- Parkinson Community – 741 public profiles, 4161 profiles only visible to PLM community
- Fibromyalgia and Chronic Fatigue Syndrome Community – 1592 public profiles, 12799 profiles only visible to PLM Fibromyalgia and Chronic Fatigue Syndrome community

> Launching a community site for fibromyalgia on PLM adds to the recognition of the illness in the medical community. It also has massive potential of being a crucial resource for patients that lack information and options about their conditions, by having every possible symptom and treatments laid out in one central source…this can be a great source for doctors, because knowledge and understanding of fibromyalgia among doctors can always be improved. This can be the perfect linkage between patients, their support system and health care professionals (Pat36, Fibromyalgia).

Pat36's comments on the launch of a new Fibromyalgia sub-community in PLM emphasize the structured and centralized aspect of pooling and aggregating medical information in PLM. Centralization of health data offers several benefits. It contributes to the increased disease literacy of both patients and physicians, which leads to productive decentralized decision-making about patient care between these parties. Centralization also leads to increased connectedness among healthcare actors, which is one of the most important aspects of PLM in its endeavor to cultivate dialogical relations among actors.

> I really wish hospitals would put more emphasis on coordination of care right from the start. Almost every time I've been hospitalized, I've been thrown in with an unfamiliar psychiatrist who gives me a new diagnosis and a completely different set of medications…I like being able to keep a centralized record of my mood and treatment history that I can use as a reference or share with treatment providers (Pat37, Mood).

> i like the graphs, being able to keep my records in an orderly fashion in PLM.. i pray that whatever they are researching that we all get our records in and filled out (Pat38, Mood).

Both Pat37 and Pat38 express their desire for structured sharing and the ability to have a centralized record of their disease information in PLM. While Pat37 expresses the increased disease literacy and connectedness that come with centralization of private health data in PLM, s/he calls attention to the enabling of overall coordination in the healthcare system as well as discovery of treatments and cures for diseases through centralization. The lack of connection among healthcare providers and the organization of health information are the stumbling blocks in patient care, and diminish the quality of life of patients. Additionally, Pat38 points to the ordered data that ultimately enables a smooth research process in PLM. Consequently, by creating a centralized record of their disease information in PLM, patients gain the ability to facilitate the flow of information among healthcare institutions and actively engage in distribution of their health information. Structured and centralized sharing in PLM also enables increased connectedness and coordination among healthcare actors outside of the community, and leads to increased disease literacy and awareness for both patients and physicians.

ii. Unpolluted sharing. Another noticeable observation is that PLM foregoes advertising to preserve the sanctity of community actor experiences, and relies only on word-of-mouth sustainability. Foregoing advertising on the site provides feelings of safety for patients and contributes to increased sharing of private health data; another distinction from other online virtual health communities and support groups:

> I am glad they don't sell my name and other identifiable info, but have no problem with them compiling my medical info with everyone else's. If there were a ton of ads on here to pay for the site, I probably wouldn't still be here. If selling info keeps PLM up and running without annoying pop ups and also helps with disease research, I say sell away! (Pat39, MS).
>
> I trust giving my data because the presentation of the site, with no adverts, or targeted links, it seems legit. It is also great to offer our life experience up for the greater good of research. Anonymized data profiles might be of value to other research establishments (Pat40, MS).

Both Pat39 and Pat40 acknowledge the research aspect of the organization and its selling of aggregated anonymous health information to pharmaceuticals, and appreciate the non-advertising policy of the business model adopted by PLM. While Pat39's comments point to her reason of continuous sharing and participation in PLM as the non-ad presentation of the site, Pat40's comments reveal that the unpolluted presentation of the medical knowledge and information on the site legitimizes the 'sharing' of private health data (please see more excerpts on this issue in the appendix).

Although the above comments from patients reflect the thoughts and feelings of patients about PLM's non-ad policy, which enhances their desire to continue to be a part of PLM, the same non-ad policy also applies to the patients and other actors who are willing to advertise on the site:

> I have an e-book about my life with MS, and want sell it online. Can I advertise it on PLM?..I didn't read any PLM rules saying that I couldn't advertise. (Pat41, MS)…I wouldn't if I were you...this is our safe place without advertisers...and we like it that way (Pat42, MS).
>
> Pat41, while we greatly appreciate you asking permission, our user agreement states that members are prohibited from soliciting others. If you would like to put information about your e-book in your 'about me' section of your profile, that would be fine. Forum and private messages are not appropriate places to post that material (Admin2, Admin.).

The above conversation takes place between two patients (Pat41 and pat 42) and PLM administrator (Admin2). The tension occurring between Pat41, who is willing to advertise and sell her/his book on the site, and Pat42, who disapproves this intention to advertise on the site, is due to the PLM enabled safe platform for unpolluted sharing of health data. In this dialogue, Admin2 mitigates this tension by offering an alternative platform for the patient to present (but not advertise) her/his book, which is her/his patient profile. Consequently, unpolluted form of sharing enabled and supported by PLM in the community aims to maintain interest and sharing among actors.

iii. Real-time Sharing. With PLM, patients gain the ability to connect with other healthcare actors in real-time and collaborate for research, and receive support whenever they need (real-time help). This constant and instant sharing and knowledge support among actors also factors in to keep community actors sharing and participating in the community. Through a sophisticated search mechanism, patients can have access to personal information of other patients, who have similar or different experiences worldwide. They list their symptoms, treatments that worked or did not work for them, their progression of the disease, alternative lifestyles they lead.

> I've never seen another site like this where you can come and get almost instant feedback on questions, concerns, etc. There is so much information to be had, comparisons to make, things to consider. Often you

> get better (or at least more thorough) information here than you might from a doctor! Though, you should not take anything you read here in lieu of seeing a doctor (Pat43, MS).
>
> This forum helps me more than my therapist. It is available 24/7. I can never discuss everything I want in 50 minutes once a week with the therapist so I gather strength from here. Here I don't have to see anyone physically or pretend how I am feeling. I don’t have to DO anything. No pressure (Pat44, Mood).

The above excerpts are from two different community patients. Both Pat43 and Pat44 express their feelings and thoughts about real-time sharing in PLM. Constant and instant emotional and knowledge support, and real-time commitment to patient care from other PLM’ers maintain their desire to continue to be a part of this community. Pat43’s revelation points to the advantage of this real-time sharing in PLM compared to the delayed information sharing with a physician outside of PLM. Similarly, Pat44 points to the same advantage and the issues related to sharing occurring between herself/himself and her/his therapist. Some of these issues include temporal limitations, and physical and emotional pressure associated with having to maintain a face-to-face contact with her/his therapist. Nonetheless, Pat43 points to the recognition of physician expertise along with the real-time knowledge gained in PLM, despite the many benefits real-time sharing offers compared to being stuck on only physician professional expertise. This comment again reflects the patient willingness to collaborate with physicians and complement each other’s expertise (please see more excerpts on this issue in the appendix).

iv. Anytime Sharing: Opt to participate versus Opt to detach temporarily. Another form of sharing that has the potential to enhance sharing and continuous interest in the community is the anytime sharing. The alternative to opt-in and opt-out of the system in the form of lurking and temporary detachment for the patient provide feelings of freedom to choose/not choose to share her/his private health information:

> If you aren't interested in filling out mood charts and such, and just want to take part in the discussion, that's fine. Nobody's going to make you fill out info about yourself in order to be a member here. It's just one of the things that makes this site more useful than a regular peer site…people here make an effort to

> stay informed about their illness and have great suggestions and thoughts that a therapist or support group wouldn't have (Pat45, Mood) .

Pat45 comments on a patient who is reluctant to share in PLM. Her/his comment reveals that PLM allows for ‘observation only’. That is, a patient does not feel obliged to actively participate in discussions, as happens to be the case in other support groups. PLM actors can just observe, lurk, read and listen, rather than feel the pressure to participate, hence enjoy temporary detachment (from territorialization in support groups). In addition, one does not have to complete profile information to participate in forum discussions. Pat45 lays out all of these benefits of anytime sharing in PLM as a means to encourage continuous sharing by community actors.

> I avoided support groups early in my dx since I was too afraid to see what the future might hold…When I found PLM, I see how wonderful it feels to talk w/ so many MSers about anything. I feel safe and comfortable here. Given my experience w/o joining a support group, I encourage you to give it a try… if it doesn't work out, u have us (Pat46, MS).

Pat46’s comments on a patient post asking about involvement in support groups reveal that though s/he encourages involvement in a support group as an alternative to involvement in PLM (see appendix for this dialogue), s/he tries to draw attention to the limitations and pressures that come with involvement in a brick-and-mortar support group. Face-to-face interactions in these groups possibly intensify the fear and loss associated with the disease. Pat46’s revelation reflects the distress s/he could experience in participating in a support group, where s/he lays eyes on physically disabled people and feels obliged to participate. A patient does not have to witness what the future could bring her/him in terms of her/his disease in PLM as opposed to traditional brick and mortar support groups. With the possibility of anytime sharing, PLM brings comfort to the patient and increases the likelihood of continuous participation in the community.

v. Formal and Informal Sharing. Discourses among actors also reveal that actors increasingly desire to engage in both formal and informal sharing. For example, patients adopt ironic, critical, and playful engagement with diverse modes of life, and seek friendly and humorous seriousness in sharing and suffering. They remind each other that they are there to do research and accelerate the discovery of cures, not just have fun, socialize, and seek emotional support by discussing off-topic, non-disease related issues. Yet, at the same time, this ironic engagement helps patients cope with their diseases and make the community not only a care-bear, emotional support community.

> Support & affirmation are invaluable... But don't we do each other a disservice if we simply post sympathy and "me, too" responses without trying to figure out how to get better? most members need a place to just "be", without exhortations to change, come for comfort & acceptance. They're distressed by "depressing" threads. Sadly, in the minds of many, it is an "either/or" situation (Pat50, Mood).

Pat50 discusses the value of emotional support and confirmation of one's health status, which is created with the knowledge and information gained in PLM. Her/his comments also reveal the desire to experience both conflictual and confirmative aspects of the community as a means to discover alternative ways of well-being and create a platform for those that seek acceptance as well as challenge.

> I've learned so much medically to help my MS in PLM. I have more confidence, because I can express myself here. What I say is accepted since we all are bound together by this disease, growing closer with a silent understanding and acceptance of one another (Pat51, MS).

Pat51's comments express her/his satisfaction with PLM. Her/his satisfaction goes beyond the more formal informational and knowledge value of PLM. For Pat51, the 'silent' acceptance from others in similar conditions in the community and the ability to express and be one's self are the main factors that facilitate the process of coping with the disease. As actors engage in more formal sharing of information and knowledge about diseases, medical conditions, treatments and the like, their desire for involvement in the community also involve the more informal and hedonic aspects of being ill and coping with this illness:

> I just feel that sometimes forums are way too formal and "just the facts, Ma'am" type of place. I like it here because of the friendliness, as well as the seriousness (Pat49, MS).
>
> I love PLM's openness to talk about anything. I found it depressing to focus on just the disease on other sites, so I looked for somewhere with a balance of and optimism and reality, and needed to hear more about various treatments, drugs out there, experiences and how to deal with these (Pat52, MS).

Pat49’s comments reflect the desire to seek friendly seriousness in sharing and healing, especially when sharing gets too formal in the forums. Similarly, Pat52 expresses her/his gratification of PLM’s open platform for all to engage in diverse forms of sharing. The formal way of communicating and sharing only information about the disease in other web platforms causes Pat52 to seek a place where s/he could hope for cures and work at finding cures through research and sharing of medical knowledge. Hence, s/he could experience the balanced combination of formal disease related topics and various ways of coping with diseases from other patients. Patients express that their healing process does not only involve the healing of the body through treatments and medications but also involves the healing of mind and spirit. For many, the well-being and well-becoming process involves conflict, challenge and acceptance simultaneously when sharing and forming relations in the community (please see more excerpts on this issue in the appendix). Consequently, the accommodation of both disease (e.g., scientific, cause related) and non-disease (e.g., play, fun, entertaining) related aspects of sharing serves as a potential to maintain interest and participation in the community.

vi. Material and Immaterial Sharing. Interestingly, in PLM, some patients desire to exploit their disability for material gain, and turn their participatory culture into a business phenomenon, hence leading to material manifestations of their immaterial labor. The possibility for this manifestation is an encouraging factor for sharing of private health data with others:

> They should pay us a fee for ANY information about our health. Why should PLM get all the money? How about splitting that fee with us? I cannot continue to be a part of a site whose corporate entity is financially benefiting from my disability (Pat53, MS).
>
> I understand the negative reactions to profiting from user contributions, though no one really expects monetary reimbursement, there could be an expansion of "gifts" or reward program? (Pat54, MS).
>
> we want to avoid a scenario where people enter data to get something…people may not be as careful with what they share just to get something…shared information created here is a powerful incentive for sharing. But we will be working on this. We'll be sponsoring fundraising events (Admin1, Admin.).

The above dialogue reflects patient desires to seek material gain out of sharing their health data and contributing to medical knowledge generation. Material manifestation of immaterial labor has differing degrees. For Pat53, material gain of PLM through selling aggregated patient data should also be shared with those who share their data with PLM. For Pat54, the use of reward program or gifts, rather than PLM profits, could be an incentive to increase data sharing. For patients who express the desire for these different degrees of material gain, PLM offers alternatives as a means to increase disease advocacy among patients (e.g., sponsoring patients' fundraising events or disease awareness activities), yet strives to avoid the perception of material gain as a stimulant for sharing, as observed in Admin1's comments. PLM advocates sharing for advancing medical research and increasing disease awareness, and material support (e.g., sponsorship) as an end of this endeavor. For example, PLM is one of the sponsors of the Parkinson's Unity Walk and ALS events nationwide.

While some patients discuss PLM's profit motives and express their desire to make money out of their disability, others, who do not seek material gain out of sharing their data, legitimize PLM's profit motive for the greater good of research:

> MS research is so important and if selling info to a drug company will help find a cure or advancement then go for it... I'm all about advancing science and research (Pat55, MS).
>
> PLM gives patients, providers, and people who live with them a chance to "swap meet" ideas, stories, provide support and mutual learning…Parkinson and ALS are physical ailments that are still poorly understood, and are covered by PLM. PLM doesn't pimp out our information…Mood disorders are

> recognized here as important enough to warrant a place alongside things like HIV, this says that we are, indeed, important…we are the experts. That’s why we're here (Care1, caregiver, Mood).

As observed in the above comments from a patient (Pat55) and a caregiver (Care1), the legitimation process of sharing health data and PLM making profit by selling this data has different dynamics. Pat55 legitimizes PLM’s making money out of this shared data for finding cures for life changing diseases and advancing science. Care1 legitimizes PLM’s profit making for (1) the discovery and advancement of new medical knowledge about diseases, (2) increased connectedness among different parties who have a role in the well-being process, (3) increased disease awareness and acknowledgement, (4) transparency in sharing and distributing private health data, and (5) acknowledgment of patient license.

Patients also legitimize PLM’s profit motive through quality of life, learning, and blind sharing (anonymous, aggregated sharing) generated through PLM:

> What PLM receives in terms of money doesn't compare to what I have received in terms of quality of my health…What I have learned from everyone here has been priceless. We are all research nuts, for that I am so grateful (Pat51, MS).
>
> I pay big to my doctors who are too busy…I can’t take the time to express myself and interact the way I do here for FREE. As long as PLM keeps my personal information safe they can share the info with med schools, Drug companies etc, I am very grateful for PLM and what they do for us…and a blind share is worth all my effort. If someone wants to pay for this info, then I respect that company for wanting to know how we really feel and maybe things will get better (Pat56, MS).

Pat51 draws attention to the value of research and the emphasis given on research by patients in PLM, and legitimizes PLM profits for increased quality of life as a result of sharing and mutual learning in the community. Another important dynamic in legitimizing PLM profit making out of disabled people is observed in Pat56’s comments. S/he points to the ‘free’ and ‘blind’ (anonymous) sharing, interacting, self-revelation and self-expression in PLM, which s/he is unable to receive from her/his physician. In addition, the legitimation process involves the expectation for better service from healthcare providers, who buy the anonymous aggregated patient data and process it to develop a better and empathetic understanding of diseases and the resulting improved patient care. Although there are different legitimation processes for each patient when discussing the issue of PLM being a for-profit institution, the value derived from the knowledge and experience shared, produced and distributed (immaterial labor) has both material and immaterial manifestations, all of which influence the desire for sharing and participation in the community (please see more excerpts on this issue in the appendix).

vii. From Belongingness to Connectedness in Sharing: How Connectedness intensified in and through PLM: (Patient-Physician-State-Pharma Connectedness). One of the most important factors for continuous sharing in PLM is the enabling of connecting to diverse healthcare actors through mutual surveillance tools. This desire for connectedness also serves as a potential to challenge the meaning of communing for the actors of this community.

Marketing scholars and consumer researchers have conceptualized ‘community’ as a social phenomenon outside of the organization or separate from the organization (Peñaloza and Venkatesh 2006). Communities of consumers engage in activities or negotiations that serve against the organizations or support the organizations (e.g., brand communities, star trek fans, burning man), yet practicing support and resistance outside of the organization. Through PLM community as a Web 2.0 application in healthcare and medicine, we observe a shift in the meaning of community from a social phenomenon outside of organization (Peñaloza and Venkatesh 2006) to a business phenomenon (Hummel and Lechner 2001). The organization serves as a community comprised of multiple firms (partnership with research organizations, universities, pharmaceutical firms), healthcare providers (e.g., physicians, caregivers), patients, and the organization founders and administrators. The community becomes the enterprise, not outside of the organization, and not necessarily temporally or locally bound, and not coerced to full commitment, as it allows for navigation.

In the name of discovering cures and new medical knowledge through research, PLM actors embrace alternative platforms for sharing and distributing medical experience and knowledge. For this purpose, the meaning of communing involves more concern about *connectedness* and less concern about *belongingness*[18]. The subtle difference between these two terms is the *navigation*. The ways people conceive of themselves and identification of one's self with a strong sense of belongingness to the community – as articulated in conventional views of the community[19] both in actual and virtual contexts – seem to be changing. PLM as a community organization of sharing seem to be formed not on the basis of belongingness but on the basis of being connected. Observations from PLM reveal the increased aspirations of sharing and connecting with diverse healthcare actors, and generating and distributing medical knowledge. For example, patients in PLM link and tag their other existences in various virtual spaces (e.g., myspace, facebook, youtube) and invite other actors to navigate among these virtual

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[18] Belongingness here refers to identification of one's self with the community and strong commitment to the community as the ultimate source of knowledge and experience sharing.

[19] Conventional views of the community both in actual and virtual contexts reflect emotional bonding, kinship and familiarity (Gusfield 1978; Hillery 1955), common bonds (e.g., based on common experience – Armstrong and Hagel 1996), a sense of shared identity (Fischer et al. 1996), a sense of belongingness (Wild 1981) among members of the community, gemeinshaft qualities such as homogeneity, and strong sense of solidarity (Tonnies 1957), shared values and interests, consciousness, emotional and informational support, and a sense of moral obligation to other community members (Amine and Sitz 2004; Muniz and O'Guinn 2001). Reciprocal behavior is considered a common characteristic of online communities (Karyda and Kokolakis 2008). However, some scholars suggest that online knowledge contribution by consumers occur with less concern for reciprocity and commitment or obligation or moral responsibility to the network participants (Fischer et al.1996; Wasko and Faraj 2005), changing the prior meanings of reciprocity, that is, mutual indebtedness that create strong reciprocal support among network actors (Wellman and Gulia 1999). Obligations and constrains found in traditional communities tend to become loose in online communities, yielding a sense of freedom to opt-in and opt-out of these collectivities and empowerment (Fischer et al. 1996), having both gemeinshaft and gesellshaft (more rational, impersonal, contractual and supporting individualism – Wild 1981) characteristics, and involving voluntariness and differing forms and degrees of commitment by the participants.

platforms, hence enable intensified sharing and experience. As patients keep personal information to themselves or the community actors in PLM, if they had a strong sense of belongingness, it could be expected that they simultaneously detach themselves from others in terms of sharing their private health data, hence limit navigation among alternative sources of knowledge and experience. This is due to the fact that secrecy or privacy, while bonding community actors (as personal information is only accessible by community actors), isolates the individual from others, and removes the heterogeneity of the community and interactions of actors and others (Appadurai 1991). However, in PLM, we observe a strongly instilled sense of connectedness among healthcare actors, which also helps maintain the desire for sharing in the community. As patients connect with other patients from other countries in the community, their learning experience in PLM is not only limited to sharing in and learning from PLM. They both learn from each other's experiences and research links they provide on several topics. Sharing of private health data and patient generated medical knowledge do not stay within the boundaries of PLM. Patient connectedness to pharmaceuticals, the state, and healthcare providers is also intensified by PLM. The consumer becomes less willing to *belong* to a certain culture, a society or a lifestyle; but more willing to actively *negotiate* one or more communities and become a cultural constructor, and a *player* (Bauman 1996) but always necessarily with(in) and as part of a community.

In the following section, two important issues related to connectedness will be discussed: (1) the dynamics of how connectedness is intensified in and through PLM, and (2) how patients in PLM connect with other healthcare actors as they produce, distribute and share medical knowledge:

a) Patient-to-Patient Connectedness through Intra, Inter and Outer Communal Sharing. One way of intensifying connectedness among healthcare actors is to enable the enhanced learning of the disease and improved relations with others in the sub-community, among sub-communities, and outside of the community. As patients connect with other patients from other countries in this community, their learning experience is not only limited to learning from each others' experiences in the community.

> WWW.TheVisioncommunity.com...It shows all those weird things we see when our eyes are playing tricks on us. I was able to show friends and family at last, what it's like to have impaired vision. And explain to German Doctors what I was seeing, because although my German is good i wasn't able to articulate what was happening with my eyes (Pat57, MS).

Pat57's comments reveal that s/he does not only learn from others' experiences in the community but also from several research and information links s/he finds and shares with others on several topics, which help her/him present herself/himself better to those outside of the community. Intra and inter communal learning of a disease supported with alternative sources of knowledge in the community improves patient-physician and patient-family-friend relations outside of the community, hence enhancing outer communal sharing. Patients in the community link current research and clinical trials, and stories of patients and articles, so others can learn from these links and apply the knowledge they gained from them to their conditions.

> Prior to joining PLM I considered myself a well-informed MS patient. I read voraciously and had connections with many other MS victims. PLM has made me realize how woefully uninformed I was. I have learned so much from other members-not only from their own experiences but from the multitudes of valuable links they provide on hundreds of topics. The contacts with members from other countries have been of irreplaceable value (Pat58, MS).

Pat58's self-revelation points to her/his limited disease knowledge, which s/he discovers after joining PLM and connecting to other patients globally. Her/his learning about her disease in the MS sub-community is enhanced significantly by learning from other MS patients' experiences and several external information and research links they provide on diverse topics. Patients also improve their learning with the tracking graphical tools they use to monitor their and others' disease conditions:

> I've gained a lot of insight from tracking tools, from seeing patterns in my mood cycles during the last year, and how that relates to factors like medication changes and weight gain. However, I've gained even more wisdom from the patients I found on the community forum. Not only are many patients extremely knowledgeable about their mood disorder, but there is also incredible empathy and compassion among the community members (Pat59, Mood).

Pat59 explains the learning process in PLM through tracking tools. Constant tracking of one's conditions with these tools and the resulting improved learning is one of the many ways of enhancing knowledge in the community. Pat59's comments also draw attention to the knowledge gained from other knowledgeable patients in the community, the theoretical and experiential knowledge as well as the empathy and social support.

PLM actors interact with and learn from each other both within their sub-communities and across sub-communities. Such intra-communal and inter-communal learning, sharing and collaboration serve as a potential to intensify the connectedness among healthcare actors both within the community and outside of the community:

> I am new, in the process of being diagnosed. This site is a life-line for me and I check it daily. There are people who understand what I am going through and the frustration that one feels during the sometimes long and painful period of diagnosis. I can ask the questions here that my neuro won't directly answer. Armed with more information and life experiences from all of you, I am now more prepared to sit down with him at my next visit (Pat60, MS).

For Pat60, the improved learning and social support s/he gained from others' knowledge and experiences in the community also lead to improved relations with her/his physician outside of the community. Openness in sharing and talking about her/his disease with others in the community equips her/him with more knowledge, the knowledge that s/he may not gain from her/his physician but may better connect her/him to her/his physician in their encounter.

> We're just aware of each other's moods more on here through mood charts and can empathize with each other more (Pat61, Mood).

> People with a great degree of self-awareness, not reluctant to discuss negativity but willing to examine their behavioral patterns in ways that challenge themselves and others... Why else would PLM provide concrete metrics for tracking our symptoms? How cool is it that we have indicators and trended data to support self-awareness? Let's use them better, particularly in dealing with our interpersonal relationships, and be ready to hear ideas that don't jive with ours (Pat27, Mood).

Increased disease literacy through tracking tools by PLM also increases empathy and tolerance in patient-to-patient connectedness as patients track each others' disease conditions. From Pat61 and Pat27's comments, we could infer that these disease tracking tools help improve relations and help patients recognize each others' differences when they connect to each other in forums, hence enhancing inter communal sharing. When conflicts arise in forums, these tracking tools help patients become aware of their and others' mood conditions and increase tolerance towards each other as a result.

> The power of having a community of "patients like me" was demonstrated recently when we had a user whose weight was dropping precipitously, which can accelerate a patient's deterioration in ALS. Because patients track and share their important outcome measures, another patient was able to remind him of the importance of keeping his weight up (Fdr1, Founder).

Fdr1, the founder of PLM expresses the value of patients tracking each others' disease progress through tracking tools, and shares a recent experience with an ALS patient, whose weight drop was realized by another patient. Evidently, patients contribute to each others' well-being by constantly monitoring each others' health conditions.

> This is where I come instead of self-harming or attempting suicide…People here are so compassionate, and although our lives, conditions and opinions differ so greatly, we all unite for a common cause: our wellbeing...the highlight of every third day is that I get to do my mood map, which stops me from putting myself in hospital (Pat94, Mood).

Increased self-awareness of one's condition through tracking tools also supports the patient's own well-being. Pat94 discusses how her/his life has changed and her/his well-being has improved after becoming a part of PLM. The mood map s/he creates in the community in order to keep track of her/his mood conditions serves as a life-line for her/him. S/he can constantly track her/his mood condition and act accordingly to prevent herself from a potential suicide or self-harm (please see more excerpts on patient-patient connectedness in the appendix).

b) Patient-Physician/Researcher Connectedness. PLM also enables increased disease literacy of patients and physicians through tracking tools, and help them get involved in the community and form collaborative relations with each other.

> Well done! It's such a good site... Incidentally, your site has done something I've never managed to do. I tracked down someone on the Neurodex trial. Have been trying to do that for 18 months (Res4, Community blog).

As observed in the above excerpt retrieved from a researcher post, not only patients but also researchers can track specific patients in the community. Res4 talks about how s/he tracked a patient in PLM ALS community, who is a part of a specific clinical trial, in the community. There exist several researchers in the community who are interested in forming collaborations with PLM patients to engage in medical research and recruit patients from the community for their own research.

In effect, physician-patient relations outside of the community are beginning to improve through improved learning with tracking tools:

> I have had fibromyalgia for many years, but no doctor could catch it. I thought I had arthritis. Three months ago, I took my own action and started looking up information myself. I heard about PLM on the news one night and dove into it. Then I talked to my doctor. She couldn't deny what I'd found and put me on pain medicine (Pat29, Community blog).

Pat29 tells her/his story of diagnosis to others in the community blog. The struggle s/he went through eventually led her/him to take action about her/his care due to physician inadequacy and her/his lack of knowledge about the disease. The knowledge and understanding improved as a result of her/his inclusion in PLM also helped her/him better connect to her/his physician and engage in collaborative relations. Evidently, her/his physician took action together with her/him for her/his well-being, after analyzing the information s/he delivered.

> I am so glad my dr did visit PLM and got to see firsthand how great the doctor visit sheet is a valuable tool for him and makes it so much easier than flipping thru his doctors notes to remember. This is at his finger tips and i plan on taking one every time i go back for a dr visit. Thanks again for a great spreadsheet to not only help me but help my neurologist (Pat31, MS).

Pat31 also emphasizes the value of doctor visit sheets in PLM and how it improved her/his relations with her/his physician outside of the community. In Pat31's case, we observe a double-intensified connectedness. Doctor visit sheets do not only enable enhanced patient-physician communication during their encounters outside of the community. Pat31's physician decides to get involved in the community and uses these tools to facilitate her/his communication with her/his patients and improve mutual learning. Patients invite their physicians to join the community. The site also uses new Google Mapping feature to show physicians where their local patients were, which had people queuing to see who they knew that was registered on the site.

Evidently, PLM serves as a potential to contribute to increased disease literacy of the patient and the physician. Patient disease literacy is increased through mediation between patient self-report and interpretation of private health data, which fosters patient-physician relations outside of the community. Patients become more equipped with disease knowledge and engage in proactive relations with their receptive physicians, with the hope that they earn their physicians' respect. They utilize different tools designed by PLM designers to track their and others' conditions, where they are located, and diagnosis, prognosis and future stages of diseases, and can predict what might be needed at that stage of the disease (e.g., Treatment database, Lithium study tool, Geomapping, percentile curves for patients with PLS, future state modeling for ALS patients).

Physicians also get more information about diseases by tracking down different patients with specific diseases in this community. Physicians also provide several links of information in their interactions with patients in the community. Therefore, we observe increased aspirations of sharing and increased connectedness between patients and physicians/researchers. Doctor visit sheets (capture the entire symptom, treatment and outcome changes that patients have entered in the database) and mood charts created in the community give patients voice in new ways. They help patients discover and track their progression of diseases and symptoms, compare their conditions with other patients and empathize with them (which also increases their tolerance for each other), and allow for better management of their care through this aggregated private health data. Patients also share these charts and visit sheets with their physicians outside of the community. Consequently, physicians and other healthcare professionals gain a complete outlook on the patient, including information not traditionally captured in medical records.

Observations from PLM also reveal that a ‘share this’ button on each patient’s profile enables patients to share their knowledge and experiences with others outside of the community. Physician-patient connectedness is supported in and through PLM. Additionally, patients also spread the word about PLM and invite others (medical care team members, their physicians, caregivers etc…) to join the PLM community through Invite Button in MyCareTeam section, and TelltheWorld page. TelltheWorld page includes information sheets and slides about PLM, which patients can use at support group meetings, doctors’ offices or anywhere they want to tell others about PLM. Patients can also form a care team in the community by inviting their healthcare providers, caregivers, family members and the like, to foster communication, connection, and learning of the disease. Consequently, increased connectedness through PLM is also promoted and advocated by the actors in the community.

> what about later maybe business cards we can hand out to our drs and anyone else like our support groups that would help to get the word out so just a thought…(Pat9, MS)… Janet, we hear you! We'll have news about member cards very soon! (Admin1, Admin).

In the above dialogue between a patient and PLM administrator, Pat9 advises PLM to create business cards (member cards) to use for promoting PLM, increasing awareness about their diseases as well as connectedness among healthcare actors outside of the community.

> docs and therapists ARE SENDING NEWCOMERS HERE THEMSELVES -- they take them on to the site and SHOW THEM what it CAN DO for THEIR OWN progress and support.... THAT is honestly THE BIGGEST endorsement I can FIND in PLM…(Pat6, MS).

Pat6 also points to the support from physicians for the increased connectedness among healthcare actors by PLM. Physicians also encourage their patients to become a part of PLM, hence further promote increased connectedness in and through PLM.

Another important factor that intensifies patient-physician/researcher connectedness is that PLM enables personalized medicine in healthcare by keeping a record of moods, medications and side effects over time. Physicians can observe and track the prognosis for the patient, rather than practicing under the assumption that a patient will operate exactly like every other patient they've seen. By observing disease progression together with their patients and treatments that have yielded those outcomes, patients and physicians can employ a more personalized medicine.

> My printed Doctor Visit Sheet was a real hit with the doctors in the ER and in the hospital I stayed in a few months ago. As a direct result of having a mood chart and a printed list of past medications, I was able to avoid being put on yet another SSRI and given another incorrect diagnosis. I've personally been misdiagnosed a number of times because I would go to the doctor and report how I am feeling right then (Pat32, Mood).

The above story from a patient is a good example of how personalized medicine through PLM can help increase patient-physician connectedness and improve their communication, which contribute to patient well-being. Pat32 talks about her/his recent hospitalization and how her/his record of doctor visit sheets and mood charts s/he created in PLM helped physicians in the emergency room to accurately diagnose her/him. Her/his comments on her/his past experiences point to the importance of having a centralized record of one's disease information through PLM tracking tools, rather than only anecdotally communicating with the physician about her/his disease (see more excerpts on patient-physician connectedness in the appendix).

c) Patient-Pharmaceutical Connectedness through Research in PLM. PLM community engages in the scientific discovery of new uses of existing medications, and new side effects of existing drugs, all of which may serve as a useful check for errors for pharmaceuticals. By bridging the gap between anecdote based medicine and evidence based medicine, the community also has the potential to inform and guide future clinical practice.

Ongoing clinical research by patients and other healthcare actors in this community scientifically supports off-label drug use. PLM research scientists have won the 2009 Journal of Medical Internet Research Medicine 2.0 Award with the research[20] conducted by patient-supplied data concerning secondary uses of drugs , or drugs that are off-patent and therefore unlikely to be studied systematically. Such information is then delivered to pharmaceuticals and clinicians, once again intensifying collaboration between patients and other healthcare actors. In addition, pharmaceutical companies partner with PLM to recruit eligible patients for clinical trials and accelerate clinical trial process. For example, Novartis partnered with PLM to speed up the start of a 1,200 patient study of a new medicine for multiple sclerosis (Arnst 2008). Through partnership with PLM and direct connection to the patient, pharmaceutical companies can have access to potentially high-quality and highly relevant patient-generated data, and easily recruit patients for clinical trials. In addition, partnership with PLM and easy and inexpensive

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[20] "Patients Informing Practice: Post-Marketing Drug Data in PLM, a Patient-Centered Online Community" by Jeana H Frost, Sally Okun, Paul Wicks, and James Heywood, 2010.

access to patient data (e. g, forums and patient profiles) could save years of research time to discover new drugs, reduce the cost of drug discovery, and develop more effective treatments as a result of this instant real-time feedback about their products.

> Drug companies and doctors are far from infallible, and PLM community serves as a useful check. The site is, in effect, building an enormous database of patient data that can determine whether drugs and treatments are having the desired effect. We are also engaging research-based organizations to provide insights that can lead to improved treatment options…we have already presented the PLM system for community-based patient-reported data collection at scientific meetings, as well as had some of our research published in response to a peer-reviewed article (Fdr1, Founder).

Fdr1’s comments on partnership with pharmaceuticals point to the availability and easy access to patient generated health data to pharmaceuticals. Healthcare actors including pharmaceuticals can benefit from PLM as a form of validation for clinical trials and check for errors. For them, PLM serves as a mirror to discover their flaws as well as the desired/undesired effects of drugs in the research and treatment discovery process. Scientific community is beginning to accept the value of patient generated data, and PLM positions this partnership as a source of checkpoint and hypothesis generation for future clinical trials (please see more excerpts on patient-pharmaceutical connectedness in the appendix).

d) Patient-State Connectedness. Another recent development also indicates intensified connectedness between patients and the state in healthcare through this community. Enabled by PLM, patients can directly report drug side effects to Food and Drug Administration (FDA), which may accelerate the years-long traditional clinical research process.

> Patients desperately need a way to collect reports of adverse effects from medications, a responsibility shirked by the FDA and subverted by the drug companies. Would PLM lend its platform to patient communities that have been harmed by drugs, such as those suffering from antidepressant withdrawal syndrome or tracking remedies that are not profitable for drug companies, such as supplements or exercise? (Pat16, Mood).

> We collect adverse event data and we’re in the process of working with the FDA. WE launched a pilot program in our MS community which helps patients submit treatment-related adverse events directly to FDA through our site…Understanding when these events occur helps FDA better regulate the pharmaceutical and medical product industries to protect consumer safety and bring safer, more effective

> products to market…first time ever that an online patient community has helped its members identify and report adverse events. (Fdr2, Co-founding executive).

In the above dialogue between a patient and a PLM executive, Pat16 calls attention to the need for direct connection of patients to FDA and report adverse effects of drugs, which may also eliminate the subversion by drug companies in this process. However, Pat16's comments also reveal the concern for more exploitation by drug companies, if PLM discriminates among patients who are harmed by certain medications or are not profitable enough for drug companies. Fdr2's response to this comment also reveals the importance of directly connecting patient to FDA, without the Pharma's intrusion. The launching of Medwatch system, through which PLM patients can directly connect to FDA and report adverse side effects of medications, may eventually lead to better control by FDA over pharmaceutical companies, and more effective medications. This way, patient license to become involved in clinical research and delivery of side effect information to FDA may also serve as a mirror and a checkpoint for the state to realize the flaws in the healthcare market regulation.

CHAPTER VI

FINDINGS: MESO (COMMUNITY) LEVEL LEGITIMATION PROCESSES OF SHARING PRIVATE HEALTH INFORMATION

Sharing versus Privacy?

Negotiating the 'Sharing' of Private Health Data through the 'Community'

This chapter involves the discovery of the why and how of sharing and not sharing in the community, hence the discovery of the dynamics of negotiating and legitimizing the sharing of private health information in this community. As previously discussed, observations from PLM reveal the increased aspirations of sharing and connectedness among different healthcare actors. The important issues to be discussed in this chapter relate to the institution(alization)s that maintain people in this community and motivate them to share their private health information. The dynamics of the community culture formed in PLM and how they influence the processes of the negotiation of sharing private health information will be articulated.

Initial observations on these dynamics exhibit the transformation from a desire to own and fear of losing personal health information and belonging to a community to a desire to disclose, co-own or share personal information with others, not just in the community but also in alternative (cyber)localities and with diverse healthcare actors. Community dynamics may also instill the idea that privacy is not something that is owned by a private entity but has come to be shared, collective and public, yielding shared ownership in terms of private health information. When privacy becomes a matter of shared ownership, more people permeate the boundaries an individual creates around her/his privacy and have a say in organization of one's personal information in decisions to share or not share private health data. Consequently, not just individual values but also community cultural values (re)deconstruct the meanings of privacy and organize relationships accordingly in this negotiation process. Since sharing is a communicative and a relational process, when we reveal personal information to others in the community, we invite them to cross our privacy border around that information. This process ultimately makes them co-owners of that information and assigns responsibility to the co-owners for managing (negotiating who, when, where, and how much is told to others outside of the privacy border) the flow of this information (Petronio 2002).

Privacy at a Glance. The definition of privacy encompasses the right of an individual to be left alone (Westin 1967) and ability to control flow of information about himself/herself to minimize intrusion (Warren and Brandeis 1890). Specifically, lack of control over personal information – confidentiality (Gavison 1980) – is central to the issue of privacy (Culnan 1993), along with control over disclosure of one's personal information and control over unwanted intrusion or invasion (Goodwin 1991). Privacy is also associated with freedom of thought and expression as well as freedom from surveillance, identity, anonymity, secrecy and the like (Lyon 2001; Schoeman 1984, 1992; Solove 2002). It also indicates the desire for freedom from unwanted intrusion, and the desire to avoid embarrassment over privacy asserting actor (White 2004). Westin (1967) argues that the concept of privacy encompasses individuals' desire to choose freely under what circumstances and to what extent they will expose themselves, their attitudes and their behaviors to others. Consequently, common themes that underlie the concept of privacy include 1) ***control*** over externalization of one's personal information, which 2) ***belongs to*** the person (possession) (Benn 1971, p. 8). These themes of control and belongingness to an entity clash with recent conceptions of privacy and the public. As previously mentioned, Hardt and Negri (2004) draw attention to the changes in the meaning of privacy. They suggest that in post-industrial society, the concept of privacy ceases to be about private property or possession, and the concept of public ceases to be about the control of the state and comes to signify the control of the common, which is the end result of the biopolitical production of the multitude. In addition, perception of privacy is re(de)constructed by diverse institutions, hence causing the concept become a discursive phenomenon.

Constructors of Privacy

Macro-Level Institutions (e.g., State). In the U.S., privacy is treated as a matter for contractual negotiations (Chan et al. 2005, p. 283), hence becoming a tangible entity to organize relationships. In addition, the right to protect privacy –to determine and control the fate of one's own personal information – is led by the individual herself/himself, not the state (Cavoukian and Tapscott 1995). In healthcare, enabled by new communication technologies, consumers increasingly gain control over their personal health data and management of their health**.** Nonetheless, the nation state still intervenes in the processes of protecting patient privacy, which resulted in the establishment of Health Insurance Portability & Accountability Act of 1996 (HIPAA). HIPAA strictly sets boundaries on the flow of patient health records to third parties such as insurance companies and employers. Such efforts are mainly aimed at controlling the private citizens and increasing their sensitivity about privacy. HIPAA, though considered unsatisfactory and insufficient by some privacy advocates and a stumbling block by medical researchers, is being challenged by PLM. PLM identifies itself as an opt-in service, not a healthcare provider (changes in healthcare provision), which upends the HIPAA rules for patient privacy (Goetz 2008). In the New York Times, this incident is discussed:

> PLM upends this dialectic; in technology terms, it routes around the problem. Since the company is an opt-in service and not a health-care provider, HIPAA does not apply. PLM website identifies members' cities and their ages, two of HIPAA's 18 prohibited categories of personal information. Many PLM members volunteer even more information from those 18 categories.

Micro-Level Dynamics of Privacy. In light of technological advancements, consumer fear of privacy becomes salient due to collection and dissemination of private or personally identifiable information as well as selling of this information to third parties without consumer consent and awareness by the owners of different digital platforms (Hatch 2000; Zviran 2008). The dynamics of online privacy concerns also include awareness of information collection, information usage, compensation, sensitivity of information, familiarity with the entity (Cranor et al. 1999; Sheehan and Hoy 2000; Van Slyke et al. 2006), and a sense of ownership (of instruments used for access) that provides feelings of safety (Viseu et al. 2004).

In PLM, although for the most part the privacy/sharing decision is determined by the negotiations among the community actors, this does not mean that they have no individual privacy concerns. Discourses among the actors of PLM reveal that the decisions to share/not share private health information are shaped by both individual and macro concerns[21]: (1) Patients do not want access to identity or personally identifiable information (social security numbers, mailing addresses etc.). (2) Patients fear that they would lose their jobs due to disclosure of private health information. (3) Patients fear that insurance companies may have access to patient private health information. (4) Patients seek pertinent information for their care. (5) Some patients believe that there is no privacy in today's world and we are always being watched. (6) Patients have feelings of stigma and discrimination associated with revealing information about their diseases and bodies. (7) Family members cannot relate to patients' diseases and cannot

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[21] The excerpts that support these micro concerns for privacy in PLM are presented in the appendix. Since the primary objective of this research is to discover the meso (community level) dynamics of sharing private health information, only the meso level legitimation processes will be articulated with the interpretation of relevant excerpts from dialogues among community actors.

empathize with them. (8) Some patients have physical constrains that prevent them from getting involved in sharing in PLM. (9) Patients experience feelings of denial or fear of diseases after reading patient stories in PLM.

All of these macro and individual concerns of PLM actors influence their decisions to share/not share in the community. However, the tendency of consumers to disclose their private data to others is also on the rise, specifically with the desire to disclose information for building intimate relationships in collectivities with strangers, mutual sharing and learning, and bringing their projects into life. It has also been suggested that in network society, the idea of privacy becomes less of a concern, as individuals find this public exposure a pleasurable experience (Turkle 2007) and even empowering (Dholakia and Zwick 2001). They increasingly share their experiences openly with others on a global scale. Viseu et al. (2004) suggest that although consumers are concerned about their privacy, empirical evidence reveals a notable discrepancy between privacy principles and privacy practices. In Norberg et al.'s (2007, p. 100) terms, a "privacy paradox" exists, indicating that there is a significant difference between consumer willingness to disclose their personal information and their actual disclosure behavior.

Particularly in healthcare, increased concerns about healthcare privacy do not inhibit individuals. O'Harrow (2005, p. 54) also notes "consumers often willingly, even eagerly, part with intimate details of their lives". Research (2005 National Consumer Health Privacy Survey, Forrester Research) suggests that the majority of consumers in the U.S. (59 percent) adopts a pragmatic approach, performs a benefit-risk analysis and discloses and shares personal health information especially for betterment of human lives (60 percent). Furthermore, consumers are also willing to share their data with pharmaceutical firms (27 percent) or government agencies (20 percent).

The above mentioned research efforts then lead to the argument that the issue is actually not whether consumers are more concerned or less concerned about privacy or whether privacy is lost or not. Clearly, privacy concern is omnipresent. In the past, a patient had the right to make her/his information public but this information was public only to medical professionals, other doctors, and the like. Doctors would perform medical research, use aggregated patient data and publish the results in medical journals. In addition, patient information has never been divulged to individual patient. Due to recent technological advancements, sharing of information is now performed openly, and access is open to anybody. Consequently, how public or private the data is changing and access to data is enlarged, and even detailed individual data can be accessed by anyone in the public. Hence, data is becoming more and more public and less and less private. Nonetheless, this does not mean that there is less concern for privacy. If information is owned by a specific entity or under control of a specific entity, it is private, if it is shared or controlled by all in the community, it is public (shared ownership). For example, information sharing in PLM is public (information sharing is controlled by patients, the PLM system and other actors), but either privacy (by using pseudonyms, and the system providing an anonymous environment) or disclosure is practiced. Hence, the main issue is how, in the context of healthcare, one gets to share her/his private medical information and what are the terms of negotiation of sharing between the patient and other actors in the PLM community.

Meso Level Dynamics of Privacy. Galanxhi and Nah (2006) argue that two different privacy models dominate research on privacy: Macro (societal) (Lessig 1999) and micro (individual) perspectives (Adams 1999). Lessig’s (1999) societal model converges four forces that influence privacy (law, market, social norms, and architecture/technology) and assesses how these interdependent forces in combination regulate consumer behavior related to privacy.

Hence, consumers decide to disclose their private information based on evaluation of these forces. Adams (1999) focuses on micro dynamics of privacy, and suggests that consumer perceived privacy is influenced by three elements: Information sensitivity, the information receiver, and information usage.

Privacy is not only constructed by individual expectations, concerns, and experiences, but also through discourses and practices with other people (meso level: community) and a broader macro social context. Although several scholars explored the concept of privacy from a micro and a macro perspective, they overlooked the impact of meso level factors such as communities, interactions among community actors and the community culture formed through these dialogues. Despite the concerns for privacy, community dynamics are influencing privacy saliency. Sharing of private health information is now beginning to be reorganized by meso (community) level dynamics. Initial observations reveal that in PLM, community actors come to make decisions to share/not share their private health data, which emerge from multilateral negotiations and discursively constituted subject positions. At earlier points, sharing of private health information was barely practiced due to privacy regulations and proprietary policies in healthcare. Yet, patients in PLM increasingly engage in mutual sharing of private health data and learning about diseases with others in the community. They add autobiographies to their profiles and describe their conditions in precise detail (e.g., potentially embarrassing details on patient sexual functioning, and constipation are added to profiles). Observation of interactions among community actors in forums reveals that most patients have pseudonyms, yet many of them use both their first names and their pseudonyms when discussing issues and sharing their experiences in forums. Along with sharing of personal health data and how they cope with the disease and lead alternative lifestyles, patients also share their private pictures, poems, videos (post videos about the lifestyles they lead and treatments they receive, hence narrating their everyday coping with the disease from their point of view), links to personal web pages, other social networking sites and the like. In addition, as discussed in chapter four, the amount of information patients provide in their profiles or forums increases their credibility, which is important for mentoring others and encouraging them to continue sharing their private health data. In PLM, community actors gain mutual understanding of what is to be shared, how it is shared, kept, used under what circumstances (Dourish and Anderson 2006), hence potentially leading to the interoperability and seamless flow of information and experience among actors in the network. In the following section, these meso level legitimation processes of sharing private health information (community negotiations of sharing versus privacy) in PLM will be exemplified and discussed in detail.

[Insert Table 1 about here]

Why and How of 'SHARING' Private Health Information in PLM

1- Community negotiations to alleviate privacy concerns

Although observations reveal that many patients use both pseudonyms and their real names when they share in forums, some patients in PLM still have privacy concerns and are reluctant to disclose their private health data in the community. Particularly, access to identity by others is not desired for the individual reasons stated in the above sections. In order to maintain sharing and interest in the community, patients in PLM alleviate each others' privacy concerns through technical suggestions and alternative ways to protect privacy on the Internet. When negotiating whether it is safe to share private health data in PLM, patients adopt different strategies to alleviate privacy concerns:

a. Use of unique user names to protect privacy

> Internet is like a big fish bowl. You can see what's going on in many communities you're not a part of, and for the most part, you can get in if you really want. But it is so huge, narrowing it down to a specific person you want to find takes a lot of time. Unless you've gone with a really unique user name, then you're easier to be found. Of course, if you google any of the admin here, they show up, too. they wouldn't put the rest of us in a position they are unwilling to be in themselves (Pat33, MS).

Although transparency of the Internet increases privacy salience, in Pat33's opinion, the public nature of many online communities makes it harder to pinpoint or track down a specific user. However, Pat33 alleviates some patients' privacy concerns in PLM by suggesting the use of unique user names as a pseudonym when sharing in PLM.

b. Use of common names to not be identified easily by others

> I googled my own screen name and came up with SO VERY MANY people using the same screen name everywhere on the web that I am not identifiable that way. I have a public blog where I use my real full name and I write on another site where I use my real full name (Pat34, MS).

In contrast to Pat33, Pat34 recommends that other patients who have serious concerns about sharing their personal health information in PLM choose common pseudonyms used by many others on the Internet and thus prevent access to their identity. From Pat33's and Pat34's suggestions, we can infer that both the use of very common and unique user names evidently creates a fishbowl effect. That is, users are not identified easily by others, which could alleviate privacy concerns and lead to increased sharing of private health data in PLM (see more excerpts on this issue in the appendix).

2- Private messaging as a temporary detachment

An interesting observation is that patients who are no longer willing to share their private health data or have privacy concerns do not completely detach themselves from the community but use alternative means to connect and continue sharing with others of their choosing. Below are two different cases that reflect this situation:

> I was totally annoyed by some of the topics on the board… There are OTHER places to hang out and have fun at, so I will NOT face all the STRESS and NASTINESS that seems to THRIVE HERE!!..you may still PM me, but that will be the contact UNTIL and IF things change here!! (Pat35, MS).

Pat35's comments reveal that although s/he detaches herself/himself from the MS forum due to conflict among community actors, s/he still leaves the door open for those who are interested in sharing with her/him in private. The option of private messaging enabled by PLM becomes an alternative and temporary means for her/him to keep in contact with others and continue sharing her/his experiences with others until chaos in the public forums settles down.

> If our voluntarily posted personal disease history helps stimulate new direction for research and study, that is worth it…Yet, I would not be excited to post my full name, ss#, credit card # here, that would be foolhardy and it isn't necessary anyway. We can PM each other if we want to be in closer contact. Internet is a lot bigger and potentially unfriendly but most identity theft involves financial info and there sure isn't much of that here! (Pat62, MS).

Pat62 draws attention to the value of voluntarily giving away private health data for clinical research in PLM, where anonymous aggregated sharing reinforces participation by community actors in the discovery of cures for diseases. Similar to Pat35, s/he points to the availability of private messaging option in PLM. However, for Pat62, the perceived benefit of private messaging is the enabling of deep data sharing and connectedness to others, rather than perceiving it as an escape from the chaos in forums. Although private messaging narrows down the boundaries of data sharing in the community, when privacy concerns or concerns with sharing with others are escalated, it serves as an alternative and a temporary option for those who are still willing to share with a limited number of people in the community. Consequently, the availability of the private messaging option serves as a stimulant to maintain community actors' interest in PLM and make them keep sharing through alternative means.

3- Surveillance and/through connectedness

In PLM, patients can find support, connect with other healthcare actors, and track their and others' health conditions to learn from and mentor each other. All of these factors positively influence the act of making personal medical information available to all. Below are excerpts retrieved from a dialogue in which patients discuss the motivations for sharing medical information in PLM:

> I like the fact that I am able to keep track of my MS on the profile page and I do not feel at risk because we are the ones that allow how much of our personal info is being seen by other. I believe that PLM has our best interests in mind and does a wonderful job to link us up with others and other information such as treatments, symptoms, research etc (Pat63, MS).

For Pat63, PLM is an indispensable tool to constantly track and monitor her/his disease and connect with others to share disease information. Consequently, feeling connected and empowered to make her/his own decision on the amount of disclosure of private health information, Pat63 exhibits a greater tendency to share in the community.

> I understand that fear for us is out of a need to protect us from discrimination and those who would take advantage of us. But do not these threats exist in any situation to any one, healthy or not? HIPAA is not perfect and there are many things it does not cover completely with clear language either...such as business associates…PLM offers a connection that is unavailable anywhere else in the world for us. We protect and watch over each other, check up when someone has not connected in a while...We are not afraid to share our information. We welcome the opportunity to be a part of a solution to our ills and will do so until there is a cure (Pat64, MS).

Pat64 explains her/his reason of sharing in the community as the ability to monitor one's and others' disease conditions and the resulting intensified connectedness among community actors enabled by PLM. In addition, in order to reinforce these benefits gained through sharing in PLM, Pat64 points to the state discourses of power to protect patient privacy (HIPAA), which, in her/his opinion, have several gaps that diminish the credibility of such institutionalizations. Yet, institutionalizing sharing in PLM offsets issues of privacy through the ubiquitous connectedness to others and constant and real-time surveillance of disease conditions by actors in the community.

> We need to make our medical information available for us. Because, I know that I have two doctors and pharmacies that have no way of communicating with each other. I believe in privacy in regards to my medical information, but, I know what the cost in the waste of resources for not having this information centrally located for my caregivers. And I am organized and keep all of them in the loop with copies of my test results and medicine changes (Pat65, MS).

Pat65 is trying to explain to others with privacy concerns the necessity of sharing private medical data in PLM. Similar to Pat63 and Pat64's comments, Pat65 also emphasizes increased connectedness through PLM, which is achieved through continuous practice of sharing in the community. Yet, Pat65 also draws attention to the increased connectedness among healthcare providers, not just among patients. Having a centralized record of her/his medical data as a result of constant monitoring of one's condition in PLM will eventually help intensify connectedness and seamless flow of information among her/his physicians and pharmacies (see more excerpts on this issue in the appendix).

4- Giving a face to the disease

Patient dialogues mention another reason for their continuous desire to share their private health data: The patient endeavors to put a face to the disease, and increase both individual and public literacy about the disease in order to make the disease more liveable. Putting a face to the disease has different motivations:

> I'm a very open person. MS is not a dirty secret for me. It's a tiny part of who I am…I will not keep it a secret, and giving a face to MS makes it more personal and human to others (Pat66, MS).
>
> The more I talk about living with HIV, the easier it becomes to actually live with it. An opportunity to share my story with others gives me a chance to show them the mistakes I've made and hopefully helps them to avoid making them. It also gives me a chance to put a face to the disease, humanizing it and hopefully dispelling some ignorance and fear (Pat67, HIV).

Pat66 justifies the sharing of information about her/his disease in PLM as a means to humanize and personalize the disease. Pat67 also shares her/his medical information with similar motives. That is, s/he is willing to share information to increase public literacy about the disease, diminish the fear associated with the disease, and make it more liveable as a result.

> I really don't care who knows I have MS. In fact, just about everyone knows I have it. This way, they're more educated about it…Maybe with more people being educated about what this disease does, there might be push for more funding. I even have this displayed on myspace. I think it helps bring a face to the disease. I have my profile displayed to the public and encourage people to look at and see exactly what someone with MS is going through (Pat68, MS).

Pat68, in her/his dialogue with those who are privacy concerned, explains the reasons for her/his private health information disclosure. Like others, s/he also wants to put a face to the disease and increase both individual and public literacy about the disease. In addition to others, s/he shares openly to advance research and funding for research, and to enable empathetic understanding of the disease (please see more of this discussion in the appendix).

5- Desire to seek confirmation from others

As previously mentioned, the patient in this community has a new role: S/he becomes the confirmer of one's and others' health status, and the physician's expert knowledge in PLM. Social networking enables patients to mentor and learn from others, and make decisions about their care by including others' input, other than their physicians and caregivers. For many patients, seeking validation or becoming a confirmer of one's and others' health conditions (e.g., diagnosis, prognosis, treatment) are the very reasons for their continued interest and participation in the community.

> Coming to PLM, I was actually looking for information AND validation... and I FOUND IT. Perhaps it's the REAL REASON I keep sharing MY EXPERIENCE, STRENGTH, AND HOPE through my M.S. REALITY... "WE MAY NOT HAVE IT ALL TOGETHER, BUT TOGETHER WE HAVE IT ALL" we struggle silently -- JUST LIKE LIVING IN THE DARK AGES OF BOWING DOWN TO THE POWER OF THE FIELD OF MEDICINE... the only problem being.... THEY'RE ALMOST AS LOST AS WE ARE on this one! (Pat6, MS).

As Pat6 discusses in the MS forum whether one should share her/his private information openly in PLM, s/he emphasizes that for her/him, seeking confirmation from others as an alternative to physicians and healthcare providers is the reason for her/his involvement and continuous sharing. Seeking validation from alternative sources of knowledge is an important factor in sharing medical information, specifically in the cases of not fully discovered diseases, which necessitate mutual collaboration of healthcare providers and patients.

6- Discovery of one's ailment through sharing in PLM

Another important reason for continuous sharing of private health data is that patients actually discover their ailments in this community with the help of others and engage in collaborative diagnosis of their diseases:

> When I first found PLM, I was wondering if I could possibly have MS. Patients who took the time to post so very much information on their profiles were the ones who probably helped me the most. This is a VERY puzzling disease, it even confuses medical professionals! (Pat69, MS).
>
> I just discovered that I am Bipolar II-- mostly thanks to this wonderful website and its fantastic members. I choose to see my disease as an opportunity to learn more about myself and the human condition, since the alternative view "life sucks" is rather bleak (Pat59, Mood).

Both Pat69 and Pat59 explain the reason of their inclusion in PLM and sharing their private health data as the possible discovery and diagnosis of their complex diseases with the help of PLM actors. Continuous sharing by others in the community and the extent of private health data revealed in patient profiles helps patients diagnose their diseases, which also influences these patients to continue to be a part of the community. From Pat69's comments, we could also infer that sharing and learning with in the PLM community does not only help patients understand their diseases but also physicians, who benefit from such knowledge and experience sharing and engage in collaborative diagnosis with their patients.

7- De-identified aggregated sharing

As previously mentioned, some patients in PLM still have individual privacy concerns and are reluctant to give away their health information. How does PLM alleviate this important concern, when sharing of private health information online has several risks? Many patients in

PLM argue that they feel safe since their data is aggregated, which prevents them from being tracked by others who would take advantage of their personal health data (see appendix for more excerpts). PLM lets others know up front that those who have confidentiality issues when sharing information with others should be cautious about revealing information. Information and experiences patients share in the forum and patient profiles are turned into hard data, and this aggregated data remains confidential in any use PLM makes of it. PLM does not report in a way that allows individual responses to be linked to information that could identify the actual respondent.

> Health records should be aggregated and shared anonymously. The public is the largest ongoing health study in history, only no one gets to see the data. Does pill A mix with pill B and suddenly cure an unrelated condition? Maybe it's already happening for more people if we only knew (Pat71, MS).

Pat71 points to the excessive practice of privacy in healthcare, which hinders the sharing and flow of health data and delays the research process. S/he discusses the importance of openly sharing of private health data and the resulting discovery of new treatments in PLM. However, her/his comment also reflects the importance of data aggregation performed by PLM in an anonymous way. Such anonymous and aggregated sharing may then alleviate patients' privacy concerns and encourage continuous sharing for new discoveries and exploration into untapped areas of diseases.

> PLM does an incredible job of enabling people to compare notes. Doing that while not compromising personal privacy, because we really do discuss some VERY private issues, is quite a balancing act. This is an incredible resource (Pat62, MS).

Pat62 posts her/his comments on a forum thread in which community actors discuss whether one should share her/his private health data in PLM. S/he points to the continuous and mutual learning among community actors enabled by PLM surveillance tools. Pat62 also draws attention to the very private nature of sharing in the community and that through anonymous aggregation, PLM protects patient privacy and encourages participation and sharing as a result. Observations also reveal that PLM administrators constantly request patient collaboration on this issue of privacy. They point to the need of the patient to balance disclosing personally identified information against sharing the information that will allow others to find the patient to be a "PatientLikeMe". As observed in these dialogues and the previous negotiations among patients on sharing of private data, this balancing act (sharing versus privacy) is performed both by patients and PLM administrators.

8- From proprietorship to partnership in sharing

Observations also reveal that in PLM, dialogues and communications among community actors and administrators encourage the transformation from proprietorship to partnership in disclosure and distribution of health data, which challenge the very definition of privacy: Control over externalization of one's personal information, which *belongs* to the person (Benn 1971; Culnan 1993; Gavison 1980; Goodwin 1991). Patients and PLM administrators now advocate the sharing of private health information as a human right, as was the case for privacy, and encourage more people to become a part of the community and continue sharing their health data. As observed in the dynamics of patient participation in sharing in PLM articulated so far, patients exhibit increasing willingness to embrace the responsibilization of sharing and getting involved in organizing and distributing medical health data in collaboration with other healthcare actors.

In its endeavor to promote sharing as a right, PLM has become one of the collaborating organizations responsible for writing the Declaration of Health Data Rights and launching HealthDataRights.org in June 2009. Founders of PLM have testified before the National Committee for Health and Vital Statistics at the Gov 2.0 Summit. In this testimony, the founder of PLM calls attention to the concept of sharing as a right. Her/his comments reveal that in healthcare, patients expect that healthcare providers or other third parties will not share their information without patient consent, since privacy is a fundamental human right, a right to 'not share'. This increased focus on not sharing unfortunately caused privacy to become an absolute goal to achieve. Consequently in healthcare, due to overemphasis on practicing privacy, dominant institutions in the healthcare market – with the belief that patients are not competent enough to weigh the risks and benefits of sharing – took measures to protect privacy, which led to ill intentioned privacy legislation. In this vein, PLM strives to declare sharing as a right and directs the focus on sharing for the discovery of new medical knowledge together with patients and other healthcare actors and support of the research system in healthcare, which they try to ensure with their openness and transparency philosophy.

> A modern focus on privacy as a goal has moved the line to the point that medicine is slowed, treatments are delayed, and patients die for failure to have what they need when they need it. We have substituted real harm for mostly theoretical harm. We believe that openness is much more powerful concept than privacy in medicine, and one that gives patients the power to take control of their health… We need to work on building a society where information is not used to discriminate, but to assist, support and improve. Restricting the flow of information will not advance solving this problem (Fdr1, Founder).

As observed in PLM founder's testimony, privacy as a legal and a philosophical goal in healthcare has led to discriminatory practices against patients, obstructions in real-time, real-world research process and the development process of new treatments and medications. Her/his comments also reveal that the practice of sharing and openness enabled and advocated by PLM could lead to increased patient license to manage her/his care. Such license gained through open sharing and engaging in research in PLM then contributes to more sharing and seamless flow of medical information to the related parties in healthcare.

> Thank you PLM for being there for us dealing with the devastation of the diseases on this site. As we progress, our options decrease and doctors no longer want to take on the multiple risks in treating us. Our options are not always presented to us thus comes the need for a friend who understands and cares. The

> database on PLM is huge for me, I would be lost without it. I've never felt used or anything taken from me out of context. Perhaps these hearings should ask patients what they think…..(Pat72, PD).

Pat72, after reading Fdr1's testimony, comments on PLM's declaration of sharing as a right. Like Fdr1, her/his comments also point to gaps in the current healthcare system, which heavily practices privacy, discriminates against patients, and restricts patient access to health information and data. Evidently, these gaps caused Pat72 to turn to PLM as an alternative source of knowledge and support and get involved in sharing with others, with whom s/he could empathize and develop a better understanding of her/his disease conditions. Hence, s/he supports the declaration of sharing as a right by PLM, and expresses the need to also reflect patient perspectives on sharing in healthcare in the privacy hearings by the state.

> Characterizing the right of individuals to share their health information with whomever they choose as a "regulatory escape clause" is a bit disconcerting. HIPAA in fact made it a Federal law that individuals have the right to access their information and always allowed use of the information with patient consent. Unfortunately few patients realize their rights, the process to obtain the information is not easy and the comprehensibility of the information is rarely patient friendly. We need to foster patient-driven initiatives to support improved patient care, and to enable patient engagement, which may be our greatest key to improved health care quality and services (Pat30, community blog).

In a similar argument, Pat30 expresses her/his opinions on the declaration of the right to share by PLM. S/he supports the right to share in PLM by comparing it to the right to privacy practiced in the current healthcare system. Her/his comments reveal that the right to share is heavily criticized by the influentials in healthcare. However, Pat30 argues that though HIPAA is a state regulatory act to protect patient privacy, the very existence of HIPAA actually supports the right to share. S/he calls attention to this unrealized potential of HIPAA by patients, and argues that these rights are disguised by the current healthcare system through making health data inaccessible and incomprehensible. Consequently, HIPAA is constructed to protect the patient right to privacy. We could infer from Pat30's comments that patient active and open engagement in sharing and increased feelings of license in production and distribution of medical data through PLM could lead to increased access to and smooth flow of this data by diverse healthcare actors and contribute to improved healthcare outcomes (see more excerpts on this issue in the appendix).

9- Non-dominating discourses applied by PLM

Dialogues and interactions among diverse healthcare actors in PLM also reveal that in order to establish a culture of sharing and increase and maintain the desire and voluntariness for sharing private health information in the community, PLM blurs the boundaries of coercion and consent through using non-dominating discourses and advocating cultural values (e.g., openness, transparency, personalization, and (re)signification of diseases through quality of life, hope and destigmatization).

a) Openness. As mentioned in the above section on the advocacy of sharing as a right by PLM, this community organization tries to establish this mindset among community actors with a philosophy of openness. The organization strives to establish trust in the community by engaging in an open and productive dialogue with actors in the community, and by enabling patients, physicians, researchers and business partners (e.g., pharmaceutical) to drill down into the data in the system, so they can see for themselves that the analysis performed on patient data is based on what really happened.

> …Our personal info is not used in research. The location we live in, symptoms, possible causes will help scientists learn more about the disease so that they will find the cause and therefore, get better meds, or cures. I feel much more vulnerable out in the real world sharing my concerns or being honest. Our openness and vulnerability here, is what makes this site different and special (Pat81, MS).

Pat81 shares her/his perspectives on PLM's openness philosophy and how it keeps community actors sharing their knowledge and experiences with others. S/he expresses her/his comfort of sharing in PLM due to anonymous aggregated use of private health data. Her/his comments also reveal that open sharing in PLM helps not only patients but also healthcare providers and researchers to discover the unraveled causes of diseases, which will result in more effective treatments. The feeling of safety that comes with openness and shared vulnerability associated with life changing diseases in this community maintain her/his participation in the community.

Observations in community forums also reveal that patients in PLM especially advocate open sharing of private health information as long as it (1) increases accessibility to disease related information and drives treatment research, (2) improves patient-physician relations, (3) enables both social and knowledge support among actors, and (4) stimulates patient learning about diseases in the diagnosis, prognosis, and treatment stages (see appendix for more excerpts on this issue).

b) Transparency. Transparency is considered a core value for PLM, which enables community actors to feel comfortable with what the organization does/does not do with the private health data (how it is collected, aggregated and sold to pharmaceuticals and other business partners) and leads to increased sharing in the community. On the site, PLM declares that the information they sell to their business partners includes patient outcome survey results, treatment information, symptoms, and some forum posts. They sell data to pharmaceuticals for profit and also share data with some universities and other non-profit organizations for free. PLM does not rent or sell personally identifiable information such as email addresses, birth dates, names, pictures, city (not state) without explicit consent or for marketing purposes. They anonymously aggregate all the information collected from patients and then sell this data to business partners. In addition, their agreements with these business partners also include terms of liability, that is, partners are liable if they try to identify patients based on data. If pharmaceuticals try to identify patient data, this action is considered illegal and faces stiff federal penalties.

> it's the use of the information that scares most folks imo...I am the most paranoid internet user around, saying that, PLM staff has been forthright and straightforward with how the information is used. I have 0 issues with my medicine, how my disease acts, weight, age, etc is used anonymously to other research folks, so the nameless info here is negligible…You folks at PLM have been very good at avoiding the temptation to exploit the information available to turn it into quick profit…the way you all deal with information is the main reason I put my information here instead of just leaving it blank and posting as guest or something (Pat73, MS).

Pat73's involvement in sharing in the community is based on PLM's openness about its usage of data shared (e.g., how it is collected, aggregated and sold) in the community. Despite privacy concerns, PLM's transparent business model along with its de-identified use of health data for clinical research are important factors in maintaining her/his involvement in sharing her/his private health data in the community.

> PLM's groundbreaking approach to health information is commendable. It is up-front and "transparent" in its purpose and its goals. They do not require you to provide/expose any private/personal information to become a part of the community. No one is coercing anyone, or misleading anyone…It's time we stand up and take a little risk in the hope of making this a better world for the generations to come. Hopefully, those participating at PLM will also be world-changing risk-takers too - although semi-anonymously (Pat43, MS).

Pat43 praises PLM's transparency philosophy and its use of medical information. Like Pat73, s/he also expresses the straightforward attitude of the organization in explaining in detail its operations and partnerships with other businesses. In addition, Pat43 draws attention to the opt-in nature of the organization. That is, through its core values of openness and transparency, PLM blurs the boundaries between coercion and consent. The patient is not required to disclose personally identifiable information to become a part of the community or share her/his data in the community. With privacy concerns comes the risk of sharing private health data. However, Pat43's comments reveal that although sharing semi-anonymously presents potential risks, the hope instilled in the community for the betterment of present and future human lives as a result of knowledge discovered in the community (please see more excerpts on transparency in the appendix) encourages her/him to take this risk in sharing in PLM.

c) Personalization. Patients, administrators and other healthcare actors in PLM emphasize personalization in healthcare and discuss the contribution of PLM to personalized medicine through sophisticated surveillance tools. Enabling patients to continuously monitor their own and others' disease conditions and treatments, PLM intensifies sharing and connectedness in healthcare, not only among patients and between patients and physicians, but also among healthcare providers.

> the way medicine functions nowadays, personalization is a bit difficult…The biggest payoff of personalization would be the possibility of minor side effects and treating them in a personal way...We are a complex system: body, mental and spiritual. Health system nowadays are just worried about putting out medicines and stimulating consumerism to make us dependent of them as if they were the only solution for such a complex problem due to its physical, psychological, spiritual interaction. Most doctors are worried about testing on us new and expensive pills that were not very well and deeply researched by labs but very few help us seeing the problem in a holistic view. That`s why this kind of community is important: we can discuss, see, and track information about treatments and therapies that are really functional and helpful to each other (Pat74, Mood).

Pat74's opinion of the current healthcare system is largely negative due to the system's extreme focus on consumerism and its desire to maintain dominance over the consumer, which makes personalized medicine hard to practice. However, Pat74's comments reveal that enabled by platforms such as PLM, patients can constantly watch the progress of their and others' diseases and treatments, mutually learn from and mentor each other on coping with the disease. As had been stated by other patients previously, such personalized medicine, structured and centralized records of patient health data and the resulting holistic understanding of patient conditions may eventually smooth the transition of data flow among healthcare providers and reduce potential errors (e.g, misdiagnosis, inability to diagnose, misuse or unnecessary use of treatments or medications) in the process.

d) (Re)signifying a Disease (e.g., quality of life, destigmatization, hope). PLM also instills the culture of sharing in the community through (re)signifying the meaning of life-changing diseases for patients. For this purpose, the organization uses diverse discourses:

d1) Quality of life. Quality of life and diminished concern for maximization of biological lifespan is one of these discourses, which helps establish this culture of sharing and preserve the desire for sharing in the community. PLM administrators, in their dialogues with community actors, strongly emphasize the purpose of selling data to business partners. Patient data is used to establish an understanding of the real-world medical value of products or treatments used, and to accelerate the developments of new medications. Consequently, the end goal of PLM is to enable productive conversations and increased connectedness among diverse healthcare actors and take actions on patient care and quality of life.

> Patients aren't qualified to self-report their health status: Some people I've spoken to believe that truth only lies in the opinion of a respected professional, and that self-report data is just a bunch of anecdotal evidence. Yet despite supposed leaps and bounds in evidence-based medicine, it seems bodies like the FDA are getting much more interested in quality-of-life and other "fuzzier" measures. A drug doesn't just have to have a biological effect, it has to help people too, and that's not always something you can measure with a tendon hammer and an MRI (Sprt3, support).

Sprt3's comments reflect the increasing emphasis on quality of life issues in patient care rather than constant experimentation on patients with new drugs, tests and treatments. Scientific modern medicine is considered an entity, which enforces regulations that govern conventional medical therapy through evidence-based discourse (Avorn 2000). In scientific evidence-based medicine, the dominant focus is on expanding the biological lifespan based on expert opinions and research results collected from randomized clinical trials. Therefore, patient efforts to share her/his data in PLM and engage in reporting of her/his health status carry little value in this medicinal system. Yet, Sprt3 also calls attention to the increasing interest in quality of life measures by state institutions (FDA). Similarly, researchers in PLM also put strong emphasis on quality of life and care issues, as discussed in chapter four.

In the dialogues between patients and other actors in PLM, patients also express their concerns for quality of life and enhancement of lifestyles. Patients manage their care based not only on a medical enforcement of curing the disease and maximizing their lifespan but also on a variety of factors that enhance their and others' vitality and quality of life, their knowledge about diseases, and enable them to live with their diseases better:

> For me, the key was learning how to maintain a quality of life as the disease progressed. Within weeks of my diagnosis, I stumbled upon an online ALS community called PLM. I have learned more about the real world of ALS from this one site than all other doctors, experts, and researchers combined…For the first time, I felt connected to the answer of how to live with ALS and not die of it…I know that PLM researchers collect the data generated by all of the site's membership and sell it to companies so that they might produce drugs and other quality of life enhancements.. Whether or not it ever leads to a medical breakthrough, my life has benefited immeasurably from my involvement in PLM. From my active participation at PLM, I have always remained one step ahead of ALS. I may have a terrible disease but PLM makes it much more tolerable. (Pat75, ALS).

Pat75 explains how her/his involvement in sharing and mutual learning about her/his disease with others in PLM has provided her/him with the feeling of connectedness and made her/him choose to focus on life rather than death. As patients with these life-changing diseases become a part of PLM community, their focus on quality of life is reinforced by PLM's aspiration to enhance the quality of life of patients through engaging them in research with other healthcare actors and the resulting social production of medicine. Despite the fact that ALS patients are eventually doomed to death, Pat75 learns how to live and cope with this disease through her/his active involvement in sharing in PLM, which maintains her/his interest in the community.

As the emphasis in patient care gears toward quality of life, it is also important to understand how this mindset is established in PLM and how it maintains the desire to share in the community. Observations reveal that PLM strives to maintain a lasting meaning and continuity of patients' lives and support continuous sharing and learning in the community. For example, administrators become aware of the deceased patients through other patients who know and keep track of what is going on in the network. They then keep the deceased patient's information in her/his profile and make it available to all on the site as well as on the PLM Facebook page (e.g., exhibit deceased patients' videos on how they had coped with the disease) for continuous learning.

> HIV is still here. Sometimes it feels like the media has decided that HIV is a story that's been resolved; science found the cure, so roll the credits and let's all go home. But we need to shift our views and understand that whilst we're no longer confronted by images of people dying from HIV, the people living with HIV still need our support. I'm grateful to BrightonBear for sharing his experiences with us and helping me and others understand that the story of HIV is far from over (Sprt3, Support).

Sprt3's comments reflect the importance of maintaining continuity (in terms of learning and support) in a patient's life through sharing of stories and experiences among patients. In contrast to media constructed images of dying HIV patients and the ultimate resolution of HIV through scientific evidence-based medicine, s/he points to the constant understanding and support of an ailment that could bring permanent change in a patient's life.

d2) Destigmatization. Destigmatization of a disease is another discourse utilized by PLM to promote a culture of sharing in the community:

> Here I can share my treatment with others and hopefully hear and learn from others. Perhaps PLM can transform mental illness from a pariah status to a healthy, sympathetic and hey-this-is-just-real-life status in our social fabric! Too optimistic? Nah. Just 30 years ago frontal lobotomy was a treatment of first resort for more than a few diagnoses. So here's hoping! (Pat76, Mood).

In Pat76's comments, we observe explicit hoping by the patient that PLM can put a halt to the discrimination or despising of a mental illness and resignify a mental illness to mean acceptable, and common. In hoping to achieve this future outcome, patients continue to share with and mutually learn from each other, which will reconstruct an ailment's meaning in the minds of many.

> I tend to be put-off by militancy, because it tends to polarize more than bring together and encourage understanding… stigma and discrimination will not go away overnight…there are some illnesses that carry more stigma, others are considered "ok" by society. The ones that have become "ok" have received more federal funds, better treatment, are easier to talk about, etc. while the others still remain heavily stigmatized, have fewer treatments, and are more swept under the rug (Pat77, Mood).
>
> I am all for promoting acceptance of MI and removing stigma, but I'd prefer if it were accomplished by portraying the idea that mental illnesses are just like any other medical illness (Pat78, Mood).

In discussing why patients choose sharing over privacy in PLM, Pat77 takes a more collaborative rather than an anarchist path as a means to enhance the societal understanding of a mental illness. For her/him, destigmatization of a disease will be achieved in time through changing the mindset of society about mental illnesses and eventually increase sharing, awareness, and enhanced understanding of these ailments. Similarly, Pat78's argument on removing stigma and discrimination against mental illnesses shows that destigmatization could be achieved through reconstructing a more 'normal'ized image of an abnormal mental disease in society (see more excerpts on quality of life in the appendix).

d3) Hope and Hope'ing'. In PLM, new modalities of organizing lives performed are not coded in ethos of 'loss'. Patients with life changing diseases begin to reconstruct fears of morbidity and mortality within a culture of hope, anticipation and expectation (Brown 1998; Novas 2001). How is this culture of hope established by PLM, and how does it maintain continuous sharing in the community? For example, some patients express their opinions that PLM is truly "the lock stitch in the fabric of hope" (See appendix). This hope entails the anticipation that, in the future, with the body of knowledge generated through aggregation of private health information of several patients worldwide, the medical research process would be hastened and better treatments would be generated to cure life-changing diseases. Construction of hope by the actors of the community does not just include anticipation of or wishing for future better health outcomes and human lives. Acknowledging patient license to produce and distribute medical knowledge at all times, PLM enables patients to act on their hope for the future (e.g., find a cure for the disease) in the present moment (Rose 2007), actively engage in clinical research and the discovery of new treatments. Patients track their own and others' disease progression, analyze their diseases with physicians through printouts of doctor visit sheets and mood charts, and compare what other treatments worked for others in similar conditions, hoping that this type of knowledge and experience sharing will eventually lead to discovery of new cures for ailing selves.

> In PLM, i can share what i have experienced and learned, let the newly diagnosed know they can get better, help them with their fears and let them know they will get through this. when i first came on in October....i was so scared of what had happened to me.... when i found PLM, there were others like me… now that i have gotten better from the overwhelming onset, i want to share what i have learned through each and every step of this journey. This can be so frightening and overwhelming....it's nice to know we are not alone… (Pat79, MS).

Pat79's comments reveal that through mutual sharing and learning in PLM, s/he works at dispelling the fear and uncertainty associated with the disease. By sharing her/his experiences with newly diagnosed patients, s/he endeavors to bring hope to their lives through inviting them to witness her/his journey of the disease.

> PLM is so beneficial in looking for the tools to cope with the disease. People post research and real-life patient experiences of current trials and treatments. Hope is a major focus of PLM and I encourage others to join. We are strong in numbers and we have a voice (Pat80, PLM Facebook).

Similarly, Pat80 emphasizes the importance of surveillance tools in PLM and how they enable the patient to develop various strategies of coping with the disease. Hence, patients act on their hope with increased focus on research and sharing of real-world experiences. Such acting on a hope to discover cures for disease is considered by many skeptical influentials in the market as guerilla science, which will do more harm than good in the end. However, patients anticipate that sharing and the subsequent research endeavors in this community may expel these regimes of domination that promotes fear and contestation (Fillion 2005; Hardt and Negri 2000), which is the hallmark of biopower to rule the multitude, and move towards regimes of collaboration that promotes hope and negotiation. Through these non-dominating regimes, PLM aims to alleviate the likely fear and loss of ownership of private information associated with the definition of privacy as well as mortality salience formerly stimulated by the state and other influentials in the healthcare market (hide it or lose it, panoptic fear).

10- ‘Inclusion’ as a way of energizing the community in sharing

Patients in PLM discuss the diversity aspect of the community, and many of them find the inclusive perspective of the community as an important factor that influences continued sharing and learning in the community.

> This forum is like Baskin-Robbins ice cream: Everyone represents a different flavor. There are some that are your favorites, some not, some good for you, some you need more research on, some you like to combine, some that are especially toxic for you, some you haven't met yet, etc…And all together we have created a great web site. Kind of like the squares in the quilt (Pat54, MS).

Pat54’s metaphorical comment on the difference and diversity found in PLM is a good example of PLM’s inclusion strategy. For Pat54, PLM is a field of experimenting with not only a disease but also diverse modes of life.

> I like PLM because of its diversity. You all make me think, as long as I can do that I appreciate it. I've found a lot of common ground in different people when I only saw the differences and the separation at times. I thank all of you for giving me the ability to get a glimpse of understanding the complexity that being human and sharing this life together is (Pat81, MS).

Pat81 also explains her/his inclusion in this community due to its diverse nature, people with different opinions and modes of life, which make her/him develop a holistic understanding of what others represent to her/him in their sharing and coping with the ailments.

> I am able to be as open as I am because I trust the admin to protect my info. I feel completely safe here in sharing all aspects of my illness. I’ve never felt like PLM was a business oriented place. A business usually gives you only one opinion but here we can share all opinions and be accepted (Pat82, MS).

From a similar but slightly different perspective, Pat82 feels the comfort of being open and continuing to share her/his private data in the community due to established trust by PLM to protect patient privacy. More importantly, Pat82's trust is developed based on the tolerance of different opinions and acceptance by others in this community. For this reason, Pat82 argues that rather than its business profile, PLM's social and communal profile comes to the forefront, which leads to increased sharing.

Observations in the community forum also reveal that some patients perceive PLM as the most accommodating site of any type they have found, since PLM considers patient input in various decision-making processes in the community. They argue that sufficient room exists for different opinions in the community despite the occasional fighting among patients on controversial issues. In such occasions, patients link this concept of inclusion to empathetic understanding or temporary detachment from the community through alternative paths of connection (e.g., private messaging). Patients feel that they are as they present themselves, and at times present too much of themselves with the comfort of being a part of PLM. Instead of recoiling and striking or feeling wounded, patients encourage each other to reach out in order to learn from and mentor each other. It is the diversity that energizes relations and interactions in the community, without the need for resolution of conflicting positions but the need to accept and empathize with difference (see more excerpts on this issue in the appendix).

11- Self and/through 'Other' modulation of sharing private information

Along with self-modulation, dynamics of the community culture also shape the extent and appropriateness of sharing and the type of the relationship between the discloser and the recipient of this shared private information. PLM enables community actors to have a say in the design and organization of sharing in the community, which is an important factor to encourage sharing. In the following section, how community actors engage in this reorganization of sharing will be articulated.

a) (Re)scripting the sharing. The script of sharing in the community is constantly negotiated by all actors in the community (see appendix for more excerpts on this issue). As previously mentioned, patients actively engage in organization of shared health information and forum discussions, and create solutions for making sharing easier for actors. Administrators put out new improvements and most of the changes in the design of the site come from suggestions (or problems) community actors provide.

> We're working on redesigning the forum and adding categories and user tags to posts, which should help us all to better navigate through the mountains of posts that are added each day. Can you be more specific about the areas you find "tedious"? The more specific your feedback, the more we have to work with when we try to solve the problem (Admin2, Admin.).

In Admin2's dialogue with patients, patients stress their discomfort with the current design of the forums, which tends to be chaotic and creates conflict among patients as they share their data. Since such chaos hinders the process of sharing and interacting in forums, some patients offer suggestions as a means to facilitate navigation in forums and enable a smooth learning and sharing process, which were considered as inputs for experimenting with the design of the site. In fact, as a means to encourage sharing, patients reorganize their own forum posts:

> Most people started to use tags and/or mark their posts accordingly…the topics generally state the issues so those that want to look or try to help "can" do so, those who might be offended or don't think they can help tend to skip that particular thread. I don't want others to feel they can't discuss issues they may be having and need advice or help with (Pat83, MS).

Pat83 participates in a discussion thread where patients talk about the lack of organization and the resulting feuds in the forum, which discourages patient participation and sharing of private health data. Pat83's comments reveal that to facilitate and encourage sharing, patients actively engage in rescripting of forum threads through tagging their own forum posts, so others who want to help or be helped can easily navigate in the site and do not feel excluded.

> You can clean up the forum in its current state. You all understand mental illness and patients' needs from the perspective of patients. You can identify repeat topics and reference it to a previous post, help keep conversations constructive, and clarify questions for maximal use to the community. If everyone does a little bit of that, it won't be any one person's responsibility (Admin2, Admin.).

PLM administrator Admin2's comments reveal that not only do patients desire to actively engage in reorganization of sharing, but also administrators strive to encourage actors to actively reorganize the script of sharing through instilling a sense of communal responsibilization. Acknowledging patient license and expertise that could live up to this responsibilization, Admin2 suggests that patients apply alternative ways of organizing sharing in forums to avoid chaos among actors and foster increased sharing.

b) The philosophy of light touch moderation. PLM also enables community actors to have a say in the organization of sharing private health data through light touch moderation. Administrators of the community let actors create their own norms of sharing, work out their own disputes, and decide on the extent and form of disclosing their health information. Patients in the community argue that compared to many other online communities where a moderator might have to approve every post or delete things inexplicably, light moderation in this community emphasizes that patients are the experts about their conditions, and administrators do not delete posts unless they categorically violate the user agreement (see appendix for more excerpts on this issue). This acknowledgement of patient license by the administrators in organization and design of sharing in the community is an important strategy to maintain interest in this community of sharing private health data. In the following section, the main tenets of this light touch moderation philosophy will be discussed:

b1) Tolerance for Difference. The idea of light touch moderation first and foremost reflects the need for reconciliation instead of resolution. Observations reveal that in cases of conflict among actors, PLM administrators suggest the use of private messaging. Actors could send each other discreet private messages and let each other fix their own mistakes and continue sharing their health data and experiences in the community. For the administrators and the founders, the solution lies in not resolution but acceptance of differences.

> we can come to accept the differences in each other without needing PLM staff to police the site, there will be hiccups, that's to be expected with 3000 folks here in different degrees of chronic illness and how each person copes with the problems it comes with. We can accept that each of us is different and not take anyone's view or ability that they deal with MS too personally (Pat73, MS).

Similarly, patients also advocate the recognition of differences as an act of organizing sharing and interactions in the community rather than PLM policing the community. Pat73's comment above reflects this need to maintain tolerance towards different modes of thought and organization of lives through reconciliation when conflicts arise.

To live up to their own tenets, administrators and founders express to actors that they are not keen to ban people from the community (cases of those who are lurkers or those who start feuds in forums), constantly moderate interactions or impose sullen handshake. For patients, this mid-interventionist approach to monitoring actors in forums owes its success to how it is practiced by the administrators:

> PLM's policy is standard. Policies can be changed with a flick of someone's mouse, so policy is always more about how it is enforced than how it is written. It's important that we feel safe to share intimate details of our lives with MS. It's a fine balance but I know it can be achieved (Pat18, MS).
>
> in forums, lurkers are fine, arguments are best resolved by community rather than by an interventionalist approach, and people blatantly selling things will be discouraged (although genuine members are free to share their own experiences!) (Sprt3, Support).
>
> Admins deserve COMBAT PAY when it starts to get FIRED UP around here... because I KNOW how much work goes in to BALANCING someone's FREEDOM versus the overall general atmosphere, etc... and I have always found it to be well handled (Pat6, MS).

The above dialogue among PLM support staff (Sprt3), and two patients (Pat18 and Pat6), reflects how PLM serves in the processes of community actors' interactions and sharing. The way policies and codes of conduct are established and exercised is a balancing act on the side of PLM administrators as a means to share private health data comfortably in a safe platform. This is considered a hard to achieve task by Pat18 and Pat6. However, Pat6's comments reflect the hard work by PLM administrators in applying the mid-interventionist, light touch policies and maintaining synergy in the community while striving to preserve community actors' freedom in sharing. Sprt3's comments also reflect the cases when PLM has to go a little beyond the light side, when trolls or those who are intentionally involved in the community for the wrong reasons (e.g., selling as well as preaching others to use certain products). As previously mentioned, PLM administrators encourage presentational forms of discourse among community actors when they share their private health data, and consider the light touch moderation philosophy as a means to facilitate presentational sharing and interaction in the community.

Some patients in PLM also suggest that, at times, they feel that administrators serve as a shield for those who are uncomfortable with improper posts, medical advice posts (specifically those that are promoting certain drugs or giving medical advice), which are not welcomed by the actors of the community. Administrators and community actors continuously emphasize this light moderation and tolerance (allowing others to have different opinions), and administrators are willing to police the forums only when actors cannot find a solution for disputes and explicitly seek for help from the administrators. In their dialogues with other community actors, administrators specifically state that they are not keen to be put in the position of a peacekeeper or policeman, and stress the need to collectively learn to have tolerance for different opinions and reconcile when it is called for (e.g., private messaging option is considered a good way to reconcile when conflicts arise in forums).

> PLM should not be a catch all for everyone's inner demons to be cut loose to run wild and free regardless of other people's feelings just because for a few seconds you got a "kick" out of being "bad" or whatever. I get pissy, too. I usually erase or edit comments I made that I feel need to be. Or I just try and do better in the future, apologize to the person I may have offended privately, etc…in general we are trying our best to make PLM a safe place to share information and to find "community" common ground. with freedom comes responsibility... shared, communal responsibility, not one voice acting as demi-god... (Pat84, Mood).

Pat84 acknowledges and respects PLM’s light touch moderation and its stance against constant policing of the community. Despite requests from others for administrator intervention in conversations and taking of actions when some patients create feuds in forums, Pat84 emphasizes that it is the actors’ communal responsibility to modify their own attitudes and behaviors to create a safe place for all to continue sharing (see more excerpts on tolerance for difference in the appendix).

b2) Self-censorship in and for sharing. In the above section, Pat84 drew attention to self-modification to reconcile differences as a communal responsibility. Administrators also call attention to self-modulation when interacting and forming relations with others, rather than constantly policing the community and enforcing etiquettes. Consequently, we also observe the responsibilization of self-censorship or modulation of one’s actions by PLM administrators. This responsibilization is based on the belief by administrators that community actors can develop an empathetic understanding towards each other and modulate their own actions, rather than a separate moderator constantly interfering with their sharing with others.

> Self-moderation by patients already seems to happen; if something particularly contentious breaks out it might ignite passions for a day or two, but is then left to drift down the pages until it burns out. Even better, rather than us stepping in as admins and saying what is/isn't acceptable, it's you the community that decides, and where appropriate decides when to apologize/make up following disputes. Personally I like that a lot more than the old "now shake hands and say you're sorry" method our parents tried. We do have a forum code of conduct that is more inspirational than rules-based (Sprt3, Support).

Sprt3 talks about her/his observations of self-moderation in the community, and how actors practice the act of responsibilization. Rather than taking disciplinary action against those who are rude, which could change the dynamic of the group in a way that is not desired, administrators prefer to instill in the actors a sense of responsibilization for self-modulation to work things out whenever possible in the community. Hence, PLM facilitates diverse modes of government through community (Rose 1999b), and through these non-dominating strategies (Dean 1999, Rose 1999b). The act of government in this example does not represent a unilateral or top-down process but what Rose (1999b, p. 174) calls "a double movement of autonomization and responsibilization", instilling a sense of collaboration between the actors and the administrators in organizing sharing of private health data.

b3) Aspirational rather than commanding codes of conduct. The third tenet of light touch moderation relates to the codes of conduct in this community of sharing. Observations in dialogues and interactions between community actors and administrators reveal that administrators constantly stress that codes of interactions and conduct are not about rules, enforcing others certain ways of behaving towards each other or using authority to regulate (inter)actions. The idea of light touch moderation is appreciated by several patients in the community, who compare PLM to other overmoderated voice squelching sites (please see excerpts from this dialogue in the appendix). In fact, patients, rather than standing aloof and waiting for the administrators to take a course of action in cases of conflict and feuds, are increasingly willing to become a part of this moderation. For example, some patients monitor those who attack others in forums. If these tension creators have little to no information in their profiles, patients suggest them to fill out their profile information so that this information shared with others in the community enables them to be recognized by the community. Despite PLM's light touch moderation philosophy, in extreme cases of violators of codes of conduct, PLM policies are not taken very lightly by some actors. Nonetheless, others think that the rules, whether they are invisible or unwritten, are needed to maintain order in the community and avoid chaos as a means to facilitate continuous sharing and connectedness in the community.

> It does NOT sound like censorship to me, it sounds like rules that are set about to make sure everyone receives reliable information in a non-threatening manner. If people are rude and harass others all you are going to do is make people leave the site and then who are you going to get your info from? (Pat85, MS).

Pat85 comments on a thread discussing whether PLM codes of conduct are a form of censorship. S/he is one of the many others in the community, who thinks order is desired for maintaining harmony and safety, so actors could engage in mutual sharing and learning experience (please see more of this discussion by patients in the appendix).

Patients also discuss codes of conduct and compare PLM policies with those of other online health communities. They argue that PLM's moderate protectionism is a better strategy to encourage sharing than those who adopt maximum protectionism. For example, other sites (e. g, Plaintalk) limit patient access (e.g., new members) to the forums until they meet certain requirements, such as meet and greet others, have a certain number of postings or have continuous posting in a certain time frame, and prove one is not a lurker (please see excerpts from this thread in the appendix).

> Sarcasm, degrading, lack of understanding of disability, constant policing, lack of admin education. At PLM NOT once have I been teased, or laughed at, or have the Spelling police post to correct me. I feel safe here. PLM Admins and owners are EDUCATED people, and truly care about this site. Other sites I've been to.. NOPE. From my first post here I was welcomed by everyone. I hope people stay. I need this place… the grass isn't greener on other sites, ALL have their issues....It's just different.. If you are not in a place where they understand your disability watch out (Pat86, MS).

Pat86 expresses her/his opinions on PLM policies and codes of conduct in comparison to other sites for health information sharing s/he has been to. Pat86's main reason for continuous sharing in PLM is the feelings of comfort and safety provided through PLM's mid-interventionist approach in moderation of sharing in forums and increased disease literacy and understanding by others as a result of mutual learning and sharing in the community. By emphasizing these aspects of PLM, s/he also tries to encourage those who are critical of PLM policies to stay in the community. Aspirational codes of conduct in PLM provide community actors with increased feelings of license by patients to get involved in reorganization of sharing in the community, which is also supported by PLM's responsibilization strategy.

c) Strategies to deal with controversy in forums: For the most part, conflicts and feuds in forums are major concerns in PLM, which push away some patients and discourage them from sharing their private health data in the community. In order to avoid these feuds and maintain actor participation and sharing in the community, patients also develop diverse strategies for self-modulation:

c1) Self through other realization: One of these strategies patients develop to deal with conflict in forums is the realization of one's self through others, which helps patients continue to be a part of the community:

> I have a different approach to controversy, I use discussions to realize that my emotions are still alive and working, that knowing I can feel happy, sad, angry, or just not lonely with people who KNOW how I feel and really understand is a positive for me. I can say I never have left this site unfulfilled. knowing that someone will be here anytime is security for me even if I say nothing (Pat87, MS).

In a discussion thread about how to deal with controversy in the MS forum, Pat87 follows a strategy of self realization, which is triggered by dialogues and interactions with others in the community. Her/his comments also reveal that in PLM, s/he feels safe to be a part of this community due to constant and instant support from others, which does not require active participation in discussions on her part. S/he is also enabled to reflect her/his emotions in dialogues with others through using those who understand what s/he is going through or how s/he is coping with the disease as a mirror to better assess her/his real self and ailing self.

c2) Temporary detachment from the community to deal with conflict. Observations also reveal that Mood community has the largest number of feuds and conflicts among actors, which some patients ironically attribute to their mental ailments. When feuds escalate in the Mood forum, community actors develop different strategies to detach themselves temporarily from the community and use this temporary privacy away from the community as a means to preserve their involvement in the community:

> I left for a couple months because I was upset by a storm similar to what we just experienced. I returned because I missed the community, and I decided this is a safe place to learn how to deal with conflict, anger and confrontation. I've been here since PLM went "live" after their testing. From what I've seen, people will often need to take a break and return. That's ok. Sometimes we gain new insight, and need time to process what we learned here. Sometimes we just need to go to the privacy of our own room instead of living in the open community (Pat50, Mood).
>
> I've gone through phases where I didn't feel like posting and sometimes I find "lurking" more helpful. I'm over sensitive and need to slow down sometimes. If I feel hurt or personally attacked it's like a mental roller coaster in my mind gaining momentum until it's this huge ordeal that it didn't need to be. Then I say things I regret later (Pat88, Mood).

Excerpts from Pat50 and Pat88 reveal that Pat50 temporarily detaches herself/himself from the community due to the feud going on in the community, and is willing to have temporary privacy away from this public forum in the community. However, her/his decision to return to the community and continue to be a part of it is based on the feelings of safety s/he had experienced in this community, which serves as an opportunity to deal with conflict in the forum. Pat88, on the other hand, chooses the option of lurking rather than posting or participating in order to modulate her/his reactions when conflicts arise in the community. The opt-in nature of the community provides community actors with feelings of safety to share with others and continue to be part of the community. They are able to practice both privacy and sharing through different strategies they develop, which in turn intensifies their desire to come back to the community and continue sharing.

c3) Private messaging as a temporary detachment to deal with conflict. As mentioned in the above section, patients have the option of practicing both privacy and sharing in PLM. When they want to have some privacy away from the community in order to deal with conflict in forums, they choose the option of private messaging to temporarily detach themselves from forums. However, they stay connected through messaging others in a private manner:

> Thank god for PM on PLM for me that's the only real way to have the opportunity to develop stronger individual relationships, trust, and sharing privately without 20 other people jumping in and hijacking a thread that is helpful to me and another. We can't really develop skills and relationships without the privacy and progressive sharing of ideas and that eventually influence how we present ourselves on the forum... at least for me (Pat84, Mood).

Pat84 perceives private messaging option as a way to improve on her/his relations with others in the community. S/he prefers private sharing with others rather than constantly encountering attacks from others in public forums. In PLM, privacy is deemed important for self-presentation in forums, since it enables the experimenting with and developing skills to cope with conflicts in forums.

c4) PLM: practice for real life, and practice a different life. For some patients, their involvement in PLM serves as an opportunity to grow and look at their illnesses constructively rather than just acknowledge the fact that they are ill. They have the opportunity to use this community as a class room to recognize differences, learn to reconcile these differences, and modulate their own actions:

> This is a community for people with mood disorders. We don't have to be on our best behavior. But it can be a place where members learn how to behave/modulate their behavior, to better interact in society. This is a good place to practice…If I'm always the fixer, always shoulder the responsibility to make everything better, even to the point of destroying myself, is that healthy kindness and concern, sainthood, or pathology? If we merely continue those roles here on site instead of trying new ways, don't we continue our textbook mood disorder dysfunctional behavior? We're all in the same boat, and understand each other. Seems like a good safe place for me to practice "doing it differently". That's scary for me, but I want to be better than I am. That requires change....(Pat50, Mood).

Pat50's thoughts on her/his involvement in PLM reveal that s/he perceives PLM as a platform to cope with interpersonal problems, accept differences, modulate her/his own actions, and get ready for the real world. Rather than feeling the pressure to perform socially constructed 'proper' roles in the community, s/he is enabled to experiment different roles and practice both what is proper and what is possible when sharing with others in PLM. Experimentation with different roles and modulation of one's behaviors in the community also help community actors improve on their relations with others outside of the community.

Why and How of 'NOT SHARING' Private Health Information in PLM

The dynamics of 'not sharing' and 'sharing' in the community are not mutually exclusive. Some of these dynamics specifically cause actors to permanently detach themselves from the community and discontinue sharing their private health data. These meso level factors of 'not sharing' as well as the strategies developed by both administrators and patients in the community in order to prevent 'not sharing' in PLM are discussed in the following section.

1- Cliquing away Inclusion

Observations reveal that the existence of cliques in the community restrains actors (especially new actors) from sharing and participating in the community. Although some actors still value the inclusive aspect of the community that accommodates diverse opinions and modes of life, others shy away from the community.

> MS forums seem to have more than their share of people who form cliques. Therapy cliques. Who has the worst MS cliques. Oldtimers versus newcomers cliques. I have no idea how to improve on this either. It keeps me lurking more than posting. Entirely too much stress for me (Pat18, MS).

> PLM has become way too 'white middle class Christian' and 'mindlessly pro-American. Goals of PLM have been subverted by those who are only looking to broadcast their limited views of the world and get offended when diversity rears its ugly head. The topic is MS and how to live with it and not keeping to the 'party lines' ...You've shut out most of the rest of the world (Pat4, MS).

As observed in the above excerpts, various cliques formed by community actors discourage Pat18 to share her/his private health data in the forum and interact with others in the community. Pat4's thoughts on the effects of cliques on sharing in the community are similar to those of Pat18. In contrast to Pat18, though, Pat4 takes a bitter stance by claiming that the formation of class-like cliques in the community has damaged the concept of inclusion and diverted the ideal(s) of PLM so that actors feel discriminated against and discontinue sharing as a result. On the other hand, some patients believe that the perception of cliques is possibly a facade:

> I don't think there are cliques in here so much as there are some people who post way more than "average", and thus tend to get more responses since everyone knows them (due to the volume of their postings)…No one here is intentionally alienating anyone else, I don't think, and as long as things are pointed out gently and in a respectful way, everyone gets along okay. I'm sorry you are feeling ignored. Is there a particular post somewhere you feel got missed or ignored? (Pat89, Mood).

In a dialogue with a new patient, who feels ignored and is willing to detach completely from the community for this reason, Pat89 strives to maintain this new patient in the community by drawing attention to some community actors' more than average participation, which leads to the false perception of cliques in PLM.

> For those that feel there is a clique at PLM, to me its way off. I view them as a certain group needing something different from PLM. The definition of a clique at PLM to me is a group of people interacting to fill their needs. We do have the choice to skip a thread that makes us feel a little uneasy. There are a lot of off topic threads that are bothersome to some of you. Off topic threads do to some of us what knowledge threads do for some of you. They are helping so many of us (Pat90, Mood).

Pat90, on the other hand, has a different definition of a clique in PLM. S/he comments on a forum post by another patient, who is discouraged to post in the forum by others who discuss off-topic (non-disease related) issues. Pat90's comments reveal that actors become involved in the community for different needs (e.g., support, information, acceptance, fun seeking, chatting), which leads to the false perception of a clique; in this case an off-topic clique that has little to do with sharing information about the disease. For Pat90, diversity of needs creates cliques naturally in the community, which should not be alienating for other actors but should encourage navigation in the community to satisfy these needs.

Whether they are formed due to some actors' frequent participation or involvement in the community to fulfill diverse needs, cliques are a major concern for those who want to become a part of the community and continue sharing in the community. Community actors strive to prevent these cliques by recommending those who are discouraged by the existence of cliques to get involved more in the community and participate frequently:

> Those who feel strongly about cliques (which may or may not exist) and get offended, also don't feel welcome here or connected to anyone, hence probably don't read the boards with the frequency that others do…the best way to get past the perception of cliques is to just keep trying to find places to post and contribute to the conversation whenever possible. some are so active on the site that a lot more people talk to them, while others contribute a bit less and can feel unnoticed, since their posts are "skipped over" without comment while several people comment on someone else above/below them that is more "popular" or well known on the site (Pat89, Mood).

In her/his comment cited earlier, Pat89 had drawn attention to the perception of cliques due to those actors who participate and share more in forums, hence get recognized more by others than those who contribute less. Pat89's above comments include her/his suggestions to those who are bothered by the existence of cliques in the community and do not participate or share with the rest of the community. Patients who are discouraged by cliques could navigate the site to find forum threads that would suit their interests and engage in increased sharing and interaction with others in those threads, which will result in recognition by others and eliminate the false perception of cliques (see more excerpts on this issue in the appendix).

2- Dealing with Trolls or 'Poseurs': Pay No Attention, Police, and Present

Trolls are also a major obstruction to sharing and engaging in dialogues with community actors in PLM:

> We should be cautious. We are generally more vulnerable and have a lot of personal info on our profiles that we wouldn't normally share. Our eagerness to help others in pain can also make it easy for us to get sucked into a mind game. Beck's advice to ignore suspicious posters, IMHO, is the best way to deal with this. Having said all that, I think that PLM is the closest we can get to having a safe place where we can be open about ourselves (Pat91, Mood).

Pat91 points to the danger of trolls in the community when patients share the most intimate details of their lives. Despite the feelings of safety and openness s/he experiences when sharing in PLM, the very private health data shared in PLM is vulnerable to this danger, which could alienate actors from the community. Hence, the strategy Pat91 adopts when dealing with trolls is simply ignoring them in order to maintain the desire to continue to be a part of the community and share with others.

> We have a few ways of preventing trolls. First, our community members, who are a very switched-on group. If anybody posts something suspicious or overtly commercial we normally hear about it in a matter of minutes and are able to respond appropriately. Secondly we have a clear emphasis on sharing what has been helpful, but we ask people not to try and persuade others to change their regime; that is a choice for them to make. Finally, by giving patients the tools to look at each other's outcomes, we encourage people to put their data where their mouth is. If "supplement x" has worked for them, we'd encourage them to enter in their data so other people can see for themselves (Sprt3, Support).

Sprt3 comments on a discussion thread concerning the risk of trolls in the community posted by those who are discouraged to share in the community due to the existence of trolls. From her/his comments, one could infer that patients and PLM administrators take a collaborative stance against trolls. Some actors in fact perform the police role when they detect trolls, and immediately notify administrators to take the necessary course of action. In addition, administrators prevent trolls by encouraging patients to engage in presentational forms of sharing and not preaching others or forcing them to try certain medications (see more excerpts on dealing with trolls in the appendix).

3- Unfit Connection

3a) Undiagnosed, Newly Diagnosed, and Less Progressive Stage Patients.

Observations in dialogues between patients and PLM administrators in the MS forum reveal that administrators emphasize the fact that PLM is a site to help people dealing with MS, whether officially diagnosed or not, and that that several people in the community have not been diagnosed. Administrators encourage continuous sharing in the community by constantly emphasizing the objective of PLM: PLM is a site to learn, not just participate and share. Nonetheless, some patients still feel discriminated against due to their disease stages. For example, undiagnosed or less progressive health stage patients feel disconnected and are discouraged to share in the community:

> I'm new to MS, and don't have any valuable input or anything intelligent to say regarding topics in the forum. Perhaps, these "people" are just curious about a disease process they don't understand, perhaps they have a family with it and they are looking for more info, or they are like me and are gathering information and offering support or guidance when they can (Pat92, MS).

Pat92 is involved in the community only as a lurker due to her/his belief that her/his contributions will not be considered valuable, since s/he is a newly diagnosed patient. Therefore, s/he does not see a fit with the other community actors in the forum and justifies her/his lurking behavior as being only interested in receiving information and learning more about the disease. As previously mentioned, PLM allows for 'observation only' and enables community actors to participate only as a lurker during their learning stage in PLM. Observations in forums also reveal that in this learning process, other community actors come into play to encourage sharing from these lurkers and have them reveal more information about their diseases so that they could contribute to their learning process and support them.

> there is no real room for ppms'ers here… several members have shown me that PPMS'ers are not the same therefore our opinions are unimportant. They will have their sterile forum… we have been chased out made to feel unimportant and unwanted by the general consensus of the board (Pat26, MS).

Similarly, Pat26 feels left out from the community and discriminated against because her/his less progressive disease stage is perceived as unimportant by others. Such discrimination discourages other actors to share their experiences in the community and makes them feel that their contributions will not be valued due to their lack of expertise. However, there are also patients who do not feel such discrimination and that the site is for people with different needs:

> PLM was more comforting to me them anything else. Here you have people with varying degrees of MS. when i was not dx yet, their help guided me. They invisibly held my hand. Their words and guidance came with me to my doctor visits…This group isn't just for rrms! This site isn't just for ms!!! If it was then it would be a medical site with just ms information (msn health) (Pat93, MS).

> Tbishop, I'm so glad you're staying. There are so many just like you here…Dx process takes so long for some. You may learn things here you can bring to your neuro's attention and might lead to your dx. I've enjoyed your posts. We all, dx and un-dx, need each other! (Pat5, MS).

Pat93 is a patient who does not feel left out or unfit due to her/his disease stage. Her/his sharing experience with other PLM actors reveals that they help her/him diagnose her/his disease as a result of her/his continuous sharing with them. Equipped with the knowledge gained as a result of sharing and mutual learning with others in PLM, Pat93 also makes her/his doctor visits a productive encounter. Her/his comments also reveal that PLM is for people with different needs, and s/he is able to fulfill these needs, whether it is information, knowledge, confirmation or support need. Similarly, Pat5 comments on a patient, who was first reluctant to stay in the community due to feeling disconnected because of her/his undiagnosed status. From Pat5's comments, we could infer that both diagnosed and undiagnosed patients are welcomed to the community, and their lurking behavior just to learn about the disease is accepted by others in the community. Once again, other community actors encourage these patients to share and reveal as much information about their diseases as possible as a means to engage in mutual learning and collaborative diagnosis with them in the community.

> I sat here for a few days without posting just to see what it was like, but then I decided to plunge myself into the deep end…Posting things on here has made me understand everything about my condition a lot more. I ask my ridiculous questions about my conditions here first, and then ask my psychologist... (Pat94, Mood).

Similarly, Pat94's comments reveal that the more patients participate in discussions and share their private health data in forums, regardless of their disease stage, the more their learning about the disease is enhanced, which eventually help patients make more informed decisions with doctors.

Some patients from the Mood community also discuss and compare the dynamics of the Mood community with those of the MS community (please see the appendix for patient excerpts from this dialogue). Briefly, Mood community patients argue that there are more actors and more contribution from actors in MS. Many people in MS, although undiagnosed, still post in forums and share their knowledge and experiences to learn more about their conditions. MS community actors tend to be more open when sharing, and are also advocates of disease awareness events. Undiagnosed patients are asked to complete profile info, so others can understand their situation better and offer help. Consequently, the MS community is more learning and mentoring oriented (both for diagnosed and undiagnosed patients), more participatory and more open compared to Mood community. Yet, community actors expect that those who need help and understanding need to disclose more information about themselves, hence contribute more in the forum discussion whether they see fit or not. Their strategy is to encourage them to complete their profile information, reveal as much detail as possible about their diseases, and participate more in forums so that they break the boundaries of seemingly disease stage related cliques and obtain the benefits of increased disease literacy and improved patient-physician relations outside of the community.

3b) Oldie-Newbie Distinction

Disease Illiteracy of the newbie. Some patients also feel disconnected and discouraged to share due to potentially realized oldie-newbie distinction in the community. The causes of this distinction are diverse. For example, when newbies first join the community, they feel scared to make comments that could be perceived by oldies as stupid or unintelligent. They feel illiterate in terms of their disease when they observe the discourses and interactions in the forum:

> This site gave me the chance to open up in ways that I never imagined. At first I was nervous about posting and didn't want to look dumb because people were using terms that I didn't know and probably should know. They were patient with me and I learned so much. Never be afraid to ask questions. This is the place to help find answers. Get involved in PLM and the wonderful people here and all of the topics that are discussed (Pat95, MS).

Pat95's story of how s/he was initially involved in PLM shows that the fear and stigma associated with disease illiteracy hold back newbies from posting in the forums and sharing their private health data. However, Pat95 suggests that newbies get involved in discussions and contribute whenever possible in order to enhance their learning and coping with the disease. Hence, once again, we observe that community actors emphasize the amount of contribution to discussions and sharing in order to rise above this feeling of unfit connection due to disease illiteracy.

> I want to let each of you know how important all of you are to us as oldies. We all had to learn by asking the dumb, stupid, irritating questions. We help each other. Even the OLDIES don't have all the answers! I'm still learning daily from all of you, new and old (Pat96, MS).

Pat96 comments on a forum post from a newly joined patient who feels illiterate about her/his disease and thus, is reluctant to share in the forum due to the fear of being perceived as making not intelligent enough contributions. As a suggestion, Pat96 draws attention the continuous and mutual learning process for both newbies and oldies in the community and that this process could be enhanced through increased sharing (See appendix for more excerpts on oldie-newbie distinction issue).

Oldie Responsibilization to increase Newbie participation. As observed in the above comments, newbies are encouraged by oldies to continue posting and sharing. Oldies provide several suggestions to increase newbie participation in the community:

> The only way to keep and grow our community is to encourage newcomers to post. But we don't want to scare them away by blowing them off. Some possible 'unwritten rules': Please read the welcome thread that explains the features of the site, Please put something in your about me on your profile, Please search the forum to see if others have already commented on your topic, Please don't get scared off by the feeling of a private club, it is not private, we have all been diagnosed or believe we have a mental illness…It might also help to start some other threads that could be used for some of the newbies. Like a please help me thread that we could try to keep on the first or second page, so that we don't have to continue answering the same help me thread. I think this would be one way that we could organize our forum…We shape the forum and simple changes could make it easier for all of us to navigate. Also to not let posts to slip down without a response (Pat97, Mood).

Pat97's suggestions to increase newbie participation reflect several newbie concerns and ways to alleviate these concerns. In doing so, both oldie and newbie interaction and collaboration will be maintained and the reorganization of the forum with the inclusion of newbies will also make navigation easier for all actors. Pat97's comments clearly articulate how this collaboration could take place by input from both newbies and oldies. Observations reveal that other oldies also come up with ideas such as delegating each other the responsibility to welcome each newbie and drop them a note every now and then to make them feel that they are not forgotten and their participation is increasingly sought. In fact, those oldies, who become welcomers for newbies, state that such welcoming and remembrance notes make newbies feel comfortable sharing.

Patients are not the only ones who assign such responsibilities to each other, oldie and newbie, to instill sharing in the community. PLM administrators also assign oldies new responsibilities to guide newbies in the community and increase participation:

> the way forums operate is largely impacted by you. I have my personal preferences for how I'd like people to use the forum, but they are just preferences. I can't make everyone fill out their profile or search the forum before they post a triplicate thread, and that's okay. You, on the other hand, have a little more power to change the tenor of conversations on the forum. if discussions are not as data-driven as you'd like, you can kindly ask people to fill out their profiles. Refer new folks to the site search and other places they can get what they need…there are other ways to use the site: keep your profile complete, PM with folks you have relationships with or people who are using treatments you are thinking about, or comment on another member's profile page...Mood community is open to anyone with or without a diagnosis. There is a point for many people where they just have questions, want to keep an eye on their changes in mood, etc. and we welcome that (Admin2, Admin.).

Referring to the community actors, Admin2 takes a constructive stance for collaboration with actors in designing and navigating the site and guiding newbies to navigate and contribute to the community. We observe an explicit responsibilization of community actors by Admin2. S/he considers patients, as participants of the community, more entitled to change the dynamics of the forum if it gets chaotic to the extent that it discourages participation and sharing from others. Admin2 lays down alternative ways (e.g., private messaging, posting to patient profiles, complete profile information) to navigate the site to fulfill different needs, and emphasizes that PLM is open to anyone regardless of one's disease stage or diagnosis condition. Administrators empower actors to actively engage in encouraging participation and redesigning the script of sharing in the community. Responsibilization by both actors and the administrators is one strategy to deal with distinctions that cause community actors to feel uncomfortable and unfit when sharing in the community. Another suggestion comes from Pat84, who stresses the tolerance for different degrees of commitment (e.g., oldie and newbie, poster and lurker) in the community in order to enhance sharing and participation by community actors:

> isn't it possible for us, old and newer, to decide to commit to PLM in several different, conscious ways... we can message lurkers personally in a forum thread we create to let them know that we're thinking of them or ask help from them…Forum is a way to see ourselves more clearly and produce better profiles through sharing. If us "old timers" don't have a sense of the importance of this then there will be a lot of attrition… (Pat84, Mood).

Pat84 suggests community actors (specifically oldies) that they need to recognize that each actor has a different objective to become involved in PLM. S/he articulates the ways this tolerance can be acted upon (e.g., check up on lurkers or those who disappear from time to time, and ask for their help whenever possible) and leads to increased sharing in the community. Being data oriented, Pat84 also promotes the perception of the forum as the means to learn more about one’s disease and reflect that knowledge gained from sharing with others in forums to patient profiles (see more excerpts on oldie responsibilization to increase newbie participation).

4- Patient and Administrator Censorship in Forums

4a) Patient bashing and bickering as a form of censorship. For some patients, tensions and feuds created in forums are considered another form of censorship to exclude others who are willing to stay in the community and continue sharing:

> If I saw this backbiting and bickering going on here when I joined back in July, I would have run as fast as I could away from here! That's censorship of another color. Bashing people and their beliefs until they are afraid to participate is NOT what PLM is about. if people cannot act like adults and restrain themselves from insulting others, those posts should be locked....or at least offenders reprimanded and barred from the site if the behavior continues (Pat98, MS).

Pat98’s comments reveal that bashing and bickering of others’ thoughts and beliefs by some patients is discouraging to those who are willing to participate in the community. In cases where self-governing is not achieved and community disruptive behavior is not abandoned, Pat98 advocates the application of suspension of community actors or thread closings by the administration as a means to maintain a safe platform for sharing and learning among actors.

4b) Administrator censorship of controversial thread topics. Specifically in cases of controversial topics (e.g., politics), community actors ask administrators to step in and take action to prevent bashing and bickering among actors. PLM administrators’ actions sometimes result in banning those who continue their disruptive behavior and discourage others from sharing, even though their disruptive behavior is first recognized by administrators through private messaging behind the scenes. Although administrators are aware that closing threads is not the best solution, they explain their reasons for such decisions as the limitation of tools and resources in the organization and the light touch moderation philosophy that favors self and communal governing. When it comes to banning actors, administrators also adopt alternative strategies in order to maintain sharing in the community. For example, rather than complete banning from the site, they deny actor access to the forum without closing their accounts and maintain consistency in the application of codes of conduct to all community actors. These ways of censorship are not taken lightly by some actors who react to these decisions by completely removing their profile information, yet continue to be a part of the community in a different capacity (e.g., only post in forums) (see more excerpts from this dialogue in the appendix).

> Some are upset with Admin1 about removing political posts and I understand why they think of it as censorship. We ask him to do this all the time though when posts get ugly and no one yells censorship. When we had "troll" problem awhile back admin had to step in because it was upsetting so many members, what is the difference? (Pat82, MS).

Pat82 expresses her/his thoughts on censorship of political threads by administrators. From her/his comments, it could be inferred that administrators step in and take action when some actors police such tension creators and report them to the administrators. In order to alleviate negative reactions to administrator censorship and convince those who remove their patient profiles to continue sharing, Pat82 draws attention to the consistent treatment of both troll and the bashing and bickering issues in forums by the administrators as a means to maintain comfort and safety for sharing in the community.

> nobody is saying you can't talk about these things! Two other people have offered a forum for you to continue your discussions. Or you can PM or email each other, or do a conference call on the issue. There are countless ways for you to continue enjoying your debating. you feel that their decision was arbitrary and exclusive. But I think a lot more people were hurt by the fractious discussions than just the two people who you feel were very vocal about disliking posts. There are many folks who post on PLM who are affected both physically and emotionally by strife and antagonism. Admins had to look at a bigger picture than the feelings of a few. I don't think it was an intentional slight or choosing to please a few at the expense of others. It was simply the best solution they could agree on in the interim, while they work on developing other more agreeable solutions (Pat43, MS).

For Pat43, solutions (or censorship in some patients' opinion) are found by administrators to these extreme cases by taking into consideration the feelings and inputs of the community at large, hence should not discourage others from sharing. Pat43 perceives PLM as a way of navigation and encourage those patients, who disagree with these administrator decisions and discontinue sharing, to find alternative ways to communicate with others and do their own thing.

Patient suggestions on exclusion strategies. Although some patients strongly argue that it is not PLM's responsibility to make time outs when conflicts arise and actors do not behave properly, others still desire to get involved in the supervision process through strategies developed with PLM administrators as a means to maintain interest and participating in the community:

> Why can't it be the people who are closed down and not the subject? Like a time out? They get a warning, and then a suspension? (Pat99, MS).

Pat99 suggests the exclusion of actors from the community through initial warning and suspension, not the closing of threads, so others could still continue to post and share ideas on that thread topic.

> I don't want to see anyone permanently banned - especially someone who has given so much of herself. Moderating a mood community can't be easy, but there must be another way. How about a PLM penalty box? Most people just need a little time to cool off (Pat28, Mood).

Pat28's take on exclusion is more moderate than that of Pat99. S/he suggests administrators that they construct a penalty box for those who cause problems in forums to have a time out, which will allow those who committed greatly to the community not to be excluded permanently from the community due to their wrongdoings in forums.

> Light touch moderation is quite wise. It's the implementation that is causing difficulties, and implementation can change. Time limited suspension would be appropriate as an intermediate level of moderation. Letting people govern themselves works fine when it is the same 50 or less folks every day. You start getting upwards of 100, hence too many names & opinions to mesh well with no control system. Filter coding can be written to either block posts containing foul language, or to simply blank out the words themselves. Gaia's censor coding allows individual users to determine how much "language" they want to see, instead of restricting what may be posted. Freedom of speech meets the freedom to see only what one wishes to see (Pat70, Mood).

Pat70's recommendations are more technical than communal in nature. S/he finds that the application of light touch moderation creates problems at times, and self-governing expectations by administrators could get unreasonable with rising number of actors. Consequently, s/he offers a technical censoring system, which will not necessitate banning people or closing threads.

Responsibilization and communal governing in sharing. As observed in the above comments, several patients develop strategies both for themselves and administrators, and both technical and personal as a means to alleviate tensions and create a supervision system that could be beneficial to the community at large and maintain continuous sharing in the community. However, administrators still emphasize self and communal modulation and governing of relations in the process of sharing:

> The time you have taken to make these suggestions shows the kind of ownership we love to see members taking for their community. It's not our place to say who is right and who is wrong. We often send PM's when we see something major happening, but everyone here has to take responsibility for their words and their actions, and work your conflicts out for yourselves. It's your community and you have a lot of experiences and insight to share (Admin2, Admin.).

Admin2 shares her/his ideas on what role administrators should play in the community in moderating the forums. S/he perceives the above exclusion and moderation suggestions from community actors as an increasing commitment to the community. However, acknowledging patient license in self and other modulation and drawing attention to the light touch moderation policy, s/he makes it explicit that community actors are first and foremost responsible for modulating their actions and behaviors in the community.

> Management chooses to enforce the breach with a light hand and via PM. The individual chooses to comply or leave. As a group, it is up to the community to decide what we expect and accept from each other in our daily interaction. Maureen rarely steps in to note we're going beyond norms of decency as suggested in the Code of Conduct (Pat50, Mood).

Pat50 also advocates communal moderation when communicating and sharing in the forums. Aspirational codes of conduct exist to support this communal moderation and governing of relations. Community actors report those who do not comply with the terms of codes of conduct to the administrators, who initially take a proactive approach (private messaging) to these issues and take action on behalf of the community at large.

CHAPTER VII

DISCUSSION

Rethinking Govern-mentality in Healthcare

New Forms of Govern-mentality through Social Media

Governing through the ‘Community’ and (Re)institutionalizing Surveillance in Healthcare. The dynamics of new roles and relations among healthcare actors in PLM also inform us about the transformations in the forms of govern-mentality in healthcare with the inclusion of diverse healthcare actors communing to organize sharing, generation, and distribution of private health data. In light of the ways business roles and relations are (re)organized in and through PLM, forms of govern-mentality, forms of how actors relate to each other in the business order constructed by PLM, seem to be changing as well. In this social media platform, a dialogical approach to (re)organizing business relations emphasizes asymmetrical and multilateral power relations and interactions.

As scholars discussed, contrary to the top-down approach of disciplinary power that controls and shapes consumer actions, govern-mentality adopts a bottom-up approach and works from the bottom up through constituting consumers as ‘free’ subjects (Rose 1999a, Zwick et al. 2008). In other words, govern-mentality refers to the mechanisms that shape the conduct of consumers without crushing their autonomous personas (Miller and Rose 2008). In these perspectives, governing of relations in co-creation yields a form of exploitation and wielding of power over consumers through enabling consumer freedom (Zwick et al. 2008) in search of their agency and realization of their liberatory potentials. From this vantage point, through co-creation, fostered by technological advances, organizations aim to look for new ways of engaging consumers in production processes through controlling consumer productive capabilities and exploiting their voluntary, cultural, social, enjoyed and free (unwaged) labor (Dyer-Witheford 1999, Terranova 2000, Zwick et al. 2008). Hence, in these perspectives, the consumer is constituted as ‘free’ to be exploited.

The limitations of these perspectives are that they fall short on providing a holistic understanding of the (re)constituted consumer and producer roles. That is, the questions of how consumers think of the ways they govern and are governed (Dean 1999) in co-creating with other market actors in communities and what participating in co-creation would exactly mean to the consumer (social and cultural dynamics of co-creation) are left unanswered in these perspectives. In addition, these frameworks articulate the processes of production in material terms, and establish govern-mentality as a one-way process: Either governing of consumers by marketers in the production process, or self-government by consumers in the form of sovereignty and resistance. This one-way process of govern-mentality yields the constitution of the consumer as “a docile and managed form of consumer life desired by capital” and the market as an intact hegemonic entity (Zwick et al. 2008, p. 32) and the sole locus of legitimation (Fırat and Dholakia 1998), despite the enabling of autonomous consumer creativity. Furthermore, as also evident in Zwick et al.’s (2008) theorization of co-creation as a new form of govern-mentality, these perspectives continue the objectified treatment of consumers, similar to Vargo and Lusch’s service dominant logic of marketing, in which consumers continue to remain subordinated to corporation interests despite the increasing emphasis on consumer subjectivity (Peñaloza and Venkatesh 2006). Nonetheless, providing subjective accounts of both consumers and marketers concerning their participation and partnership in co-creation (Arnould and Price 1993; Peñaloza and Gilly 1999) is equally important and vital to provide a holistic understanding of consumer-marketer relations and unravel the dynamics of community developments in new marketing systems (Peñaloza and Venkatesh 2006).

Consumers of the contemporary networked society increasingly desire to create diverse, meaningful and present life experiences and actively engage in design and production processes, which coincide with the shift from the Fordist and Taylorist approaches of production (capital-intensive, tangible commodities) to post-Fordist era (production of knowledge-intensive intangible value such as business intelligence, brands, community) (Arvidsson 2006; Hardt and Negri 2004). In effect, increasing desire of consumers to turn their social networking and participatory activities into a business phenomenon together with organizations turns governmentality into a shared field of practice that involves multidirectional and multilevel relations. Organizations and consumers find new and alternative ways of engaging in production processes, in which they form communities of sharing with the inclusion of diverse actors in the market. The community intervention to organizing business relations through PLM is intriguing in that the community comes to serve as a new territory for and a means of governing relations among diverse actors and institutionalizing new allegiances and responsibilizations (self and communal) (Miller and Rose 2008). As Miller and Rose (2008, p. 93) put forth, “government through community, even when it works upon pre-existing bonds of allegiance, transforms them, invests them with new values, affiliates them to new expertise, and reconfigures relations of inclusion and exclusion (responsibilization and autonomization)”. In the process of these correspondences or communications among actors, participants and the community come to make decisions (e.g., decision to disclose private health information), take actions and arrive at agreements regarding what or how they think about matters of interest to the community. These actions and (dis)agreements emerge from mutual, non-linear, and multi-way discourses and negotiations in the processes of decisions to share private health information and stay in the community, and discursively constituted subject positions. That is, subjects are constituted not only as free but also as responsible (self and communal) and licensed.

In the world of social networking and user-generated content through social media, unidirectional provisioning and overly deterministic actions of marketers seem to be waning, and the focus on consumer-marketer relations seems to be changing towards the social (Cova 2005). Consequently, reflecting the multifaceted and multilevel nature of organizing roles and governing relations among market actors calls for the theorization of govern-mentality in discursive (Miller and Rose 2008), productive (collaborative), and communal terms. Findings of this research reveal that PLM, as a new form of biosocial community, involves new interventions, forms and practices of govern-mentality among healthcare actors, which I term as *meridian govern-mentality*. Inspired by Cova's (2005) thinking of marketing systems in meridian frameworks, I draw attention to the co-production of medicine as a dialogical and a social process through PLM in the healthcare market. Consequently, in meridian govern-mentality:

- Meso level institution(alization)s also become the locus of legitimation in organizing the sharing , production, distribution of medical knowledge and experience.
- Patient as free: Freedom for the patient to opt-in and out of the system
- Patient as licensed: License gained through increased disease literacy and mutual surveillance puts patients on equal footing with physicians.

- Act of governing is a multilateral process involving diverse healthcare actors: Patient as responsible:
  - Both PLM community actors and administrators utilize self and other/communal governing strategies. (Self and communal responsibilization as forms of governing relations). The act of government does not represent a unilateral or top-down process but a process that involves "a double movement of autonomization and responsibilization" (Rose 1999b, p. 174), instilling a sense of collaboration between community actors and administrators in organizing sharing of private health data.
  - increasing patient willingness to embrace the responsibilization of sharing, generating, organizing and distributing medical knowledge in collaboration with other healthcare actors
  - PLM uses communal responsibilization strategy to involve actors by acknowledging patient expertise in reorganization and redesigning of sharing on the site.
  - Multilevel Connectedness among Healthcare Actors: Forms of governing relations in this community indicate that the act of government is not a unilateral affair (Li, 2002; Rose 1999b) (Patient-Physician-State-Pharma)

As discussed earlier, PLM enables different levels of connectedness in the processes of sharing private health information among healthcare actors and the resulting different levels of governing relations. Observations of legitimation processes of sharing among healthcare actors reveal intriguing results pertaining to how actors come to terms with practicing sharing versus privacy and continue to engage in sharing in this community. Forms of sharing in the community that encourage sharing have been discussed earlier. Some of the key forms of sharing include centralized sharing for decentralized decision making, unpolluted sharing (non-ad presentation of the community), real-time and anytime sharing (participation versus temporary detachment yet not complete detachment), formal and informal sharing, and material and immaterial sharing. All of these different forms of sharing shed light on (1) how healthcare actors relate to each other and maintain their participation in PLM, (2) how tensions/synergies that occur organize relations and interactions in these processes of sharing and relating to each other, and (3) how production and distribution of medical knowledge and experience in healthcare is organized with the inclusion of PLM in this process.

Meso level legitimation processes of sharing private health data and the relations organized around them in PLM involve differing levels of intervention among healthcare actors. In a patient-to-patient negotiation, we observe that patients alleviate each other’s privacy concerns through giving each other technical suggestions or other alternative means to protect their privacy when sharing and participating in the community. The opt-in nature of the community also creates a platform where actors gain the ability to navigate among different orders, rather than completely detach themselves from the order created by the community. For example, instead of completely detaching themselves from the system, actors use private messaging options or become only observers in the community in order to maintain their privacy temporarily. Private messaging serves as an alternative option for those who continue their participation in the community, yet in a private manner, which also help them improve on their self-presentation skills.

The most important contribution of PLM to healthcare dynamics is the intensified connectedness of healthcare actors and the resulting mobility and flow of health data through this community platform. Constant real-time surveillance of and by actors in PLM through tracking tools leads to increased disease literacy and support (social, informational, emotional) and connectedness among healthcare actors both in the community and outside of the community. Patient ability to create a centralized record of her/his health data also increases connectedness among healthcare providers with increased mobility and flow of health data. Researching and communing aspects of PLM factor in to increase sharing by actors in the community, along with giving a face to diseases through increasing individual and public literacy and empathetic understanding and humanizing of diseases.

Increased connectedness among healthcare actors in and through PLM, and the acknowledgment of patient license in these connections by community actors, PLM administrators, and healthcare actors outside of the community, influence the dynamics of governing relations in the healthcare market. By enabling intra, inter and outer communal sharing and learning, PLM increases patient connectedness to other patients worldwide, their families and caregivers, and their physicians both inside and outside of the community. Multiple ways of learning in the community help patient improve on self-presentation and disease literacy, and as a result, influence the governing of relations both inside the community (e.g., increased empathy and tolerance in patient-to-patient connectedness, and increased self-awareness of one's health condition through constant monitoring) and outside of the community (interpretation and presentation of what is learned in the community through surveillance tools to other parties outside of the community). In patient-to-patient interactions and sharing, patient motivations to share also include the need for confirmation from those who have similar conditions as an alternative to physicians, to confirm others' health status, and to discover ailing selves with the knowledge shared and gained in PLM.

In patient-to-physician connectedness, increased disease literacy and enhanced understanding of the disease by patients and physicians in the community also influence their outside community relations. Physicians/researchers can track specific patients and improve on their treatment methods. Patients can better present their conditions to physicians and engage in proactive dialogues with their physicians. The meeting of patient and physician on an equal footing brings about multi-way governing of relations in favor of negotiation and collaboration rather than contestation or emancipation/detachment. Patients, equipped with more theoretical and experiential knowledge about their diseases, increasingly demand validation of any type of claim made or information presented by other patients and physicians in the community with alternative sources of knowledge and scientific evidence. In addition, research conducted in the community serves as a form of validation and a useful check for traditional clinical trials. Connectedness between patient, PLM, and physician/researcher is supported by all these parties. Patients and physicians can employ a more personalized medicine through constant monitoring of disease progression and the resulting centralized records, which also serve as a form of validation and analysis in physician-patient encounter outside of the community. In addition, physicians, researchers and pharmaceutical firms can recruit patients from the community for their own research. Hence, patients are enabled to have increased access to clinical trials both in the community and outside of the community, which also intensifies patient-pharmaceutical connectedness.

State intervention in PLM is somewhat different. The state cannot interfere with the practice of sharing private health data, and cannot take regulatory action to protect patient privacy, since PLM is not a healthcare provider but an opt-in service. Dynamics of governing relations between patients and the state also reflect the acknowledgement of patient license gained through social networking. Patients can directly report drug side effects to FDA, which also serves as a form of validation for the state and influences state intervention in healthcare market regulation (improved state supervision of the pharmaceutical to eliminate subversion and exploitation by pharmaceuticals)

PLM intervention in the processes of sharing and connecting in the community and the resulting discursively constituted subject positions take multiple forms: (1) the freedom to opt-in and out of the system, (2) the license gained as a result of increased learning and disease literacy, which put patients on an equal footing with physicians, and (3) self and communal responsibilization[22] as forms of governing relations. For example, PLM enables a platform for de-identified and aggregated sharing in order to create a safe environment to share and prevent self-interested parties from tracking and exploiting patient data. In addition, PLM strives to establish sharing as a right versus privacy (a right not to share) for the discovery of new medical knowledge. Patients exhibit increasing willingness to embrace the responsibilization of sharing and getting involved in creating, organizing and distributing medical knowledge in collaboration with other healthcare actors, which will accelerate the medical research process and discovery of new treatments. Discrimination and delayed research process as a result of practices of privacy in healthcare, and the disguised practices of state institutions (e.g., patient non-awareness of her/his inherent rights in data sharing) to protect patient right to privacy seem to be some of the causes of patient turn to alternative sources of knowledge and support.

Continuous sharing and distribution of medical health data by patients is enabled through non-dominating discourses utilized by PLM. The values of openness and transparency adopted by the organization help establish a sense of trust among actors, enable patients, doctors and researchers to drill down into the data in the system and see how the analysis is performed based

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[22] As Shamir(2008, p. 4 and 8) puts forth, the practice of responsibilization is considered “an enabling praxis and a practical master-key of governance that operates at two levels: (1) at the level of individual actors, reconfiguring roles and identities so as to mobilize designated actors actively to undertake and perform self-governing tasks, and (2) at the institutional level addressing associations, organizations and other potential sources of authority that comprise the terrain of governance.

on real-world data. Specifically, for the actors of the community, the use of data collected matters the most and influences their decisions to share their private health data. In addition to PLM efforts to stimulate open dialogue and sharing, patients also advocate openness in order to increase accessibility to disease related information, drive treatment research, improve patient-physician relations, receive both social and knowledge support, and stimulate patient learning of diseases in diagnosis, prognosis, and treatment stages. PLM's transparent and opt-in business model (e.g., how it uses data, who are the business partners, how profit is made) and business partnerships with pharmaceuticals and other healthcare providers based on legal liability also establish a sense of trust in sharing and connecting in the community. Moreover, PLM emphasizes personalized medicine through its inclusion in the healthcare system with sophisticated surveillance tools. These tools enable patients to continuously monitor and watch their own and others' disease conditions and treatments, hence intensify sharing and connectedness in healthcare, not only among patients and between patients and physicians, but also among healthcare providers (transition of data flow among healthcare providers is less flawed when patients have a centralized record of their conditions and reduce diagnosis and treatment errors). PLM also aims to establish a culture of sharing in the community through reconstructing the meaning of diseases for patients (discourses utilized in this process include quality of life, destigmatization of diseases, and hope). For example, patient desire to share is enhanced through discourses such as quality of life, that is, increased emphasis on learning to live with diseases, and lessened concern for maximization of biological lifespan. The end goal PLM emphasizes in efforts to accelerate medical research process and development of new treatments is to enable productive conversations and actions on patient care and quality of life. To achieve this goal, PLM provides a lasting meaning for patients' diseases through enabling the continuous sharing of stories and experiences among patients. Actors in the community also emphasize increased and open sharing of private health data and enhanced mutual learning about diseases, which will eventually lead to destigmatization of a disease and increased patient quality of life and care. The concept of hope is another focus in PLM's efforts to resignify the meaning of diseases for patients and legitimize sharing of private health data. Hope and hope'ing', that is, anticipation and acting on that anticipation (Rose 2007) are the main tenets of hope based culture in PLM. Surveillance tools in PLM enable actors to develop various strategies of coping with and learning about the disease. Hence, patients act on their hope with increased focus on research and mutual sharing of real-world experiences to dispel the fear and uncertainty associated with the disease. In these efforts to enable patients to act on their hope, PLM alleviates the likely fear of loss of ownership of private data through providing alternative modalities of organizing their lives. The desire to share is created and maintained through a shift in focus from the loss of life and the loss of privacy as a result of sharing in PLM to ethos of hope that brings lasting meaning and continuity in people's lives.

Community actors' engagement in sharing is also maintained through involving them in self and/through other modulation of sharing private health data. In doing so, PLM receives input from diverse actors for reorganization and redesign of sharing in order to facilitate sharing and navigation in the forums. In this process of reorganization and redesigning of sharing on the site, PLM uses communal responsibilization strategy to involve actors by suggesting that patient expertise is able to achieve this redesigning of sharing, so others who want to help or be helped can easily navigate in the site and do not feel excluded.

Similar communal responsibilization also applies to governing of relations among community actors when sharing and interacting in the community. Emphasizing patient expertise about her/his disease conditions, PLM adopts a mid-interventionist approach to governing of relations and advocates reconciliation and empathizing with difference, rather than resolution of conflicting views. Hence, the premise of light touch moderation is the recognition of differences. In a similar vein, patients advocate tolerance for difference as an act of organizing sharing and interactions in the community, rather than PLM policing the community. Patients think it is the members' communal responsibility to perform self modification as a means to reconcile differences and create a safe place to continue sharing. Through this mid-interventionist approach, a balance between freedom of speech and synergy derived from PLM's inclusion strategy (diverse opinions and modes of life are accommodated in sharing) is maintained. Consequently, the act of governing of relations presents itself as a multilateral process involving both community actors and the administrators (Rose 1999b) through self and other/communal governing strategies.

Patients increasingly desire to police actions and take part in moderation of forums, and create aspirational etiquettes and boundaries on data sharing (to prevent preaching and giving superficial medical advice) together with the administrators. In fact, detection of trolls and other preachers is performed by patients, who then alert the administrators to take action. Such an act is supported by the administrators, who are reluctant to constantly intervene in actor interactions in the community. Staying loyal to PLM's inclusion strategy, patients also create alternative suggestions to temporarily exclude those who use bashing and bickering as a form of censorship or are not good at practicing self-governing. Hence, patients actively get involved in maintaining order in the community as a means to facilitate and encourage sharing. Especially in forums, where interactions occur among diverse actors, patients implement various strategies to deal with conflict in forums. Similarly, community actors are assigned responsibility by PLM to encourage sharing and facilitating navigation of diverse orders in the community for those who are reluctant to share in forums due to cliques and trolls and unfit connection as a result of distinctions based on disease or diagnosis stages (newbie, oldie, newly diagnosed, less progressive stage, literacy or expertise level). Administrators give patients entitlement to reorganize and change the dynamics of forums, if it gets chaotic to the extent that it discourages sharing. They also encourage presentational forms of discourses and interactions among actors in cases of trolls. Responsibilization strategy is utilized both by administrators and community actors themselves. Experienced actors suggest each other ways to increase new actor participation and show tolerance towards different degrees of commitment. Consequently, actions and (dis)agreement emerge from multi-way negotiations including self and communal governing strategies.

(Re)institutionalizing 'Surveillance' through sharing: Biosocial Surveillance. The dominance of the top-down approach in healthcare has led to the construction of patient-physician relations in a one-way surveillance in favor of the rational medical gaze, the physician. Technological and cultural transformations have moderated this top-down relation while empowering the patient to have control over her/his management of health. The rise of these mutual moderate relations between healthcare actors mainly involves more lessening of power exerted by influentials in the healthcare market on patients (accepting increased patient license). The use of social networking in healthcare presents the potentials that patients and other performers of the healthcare market engage in *mutual surveillance* of their diseases. Patients and other healthcare actors engage in *biosocial surveillance* enabled by PLM, which is a systematic, social, and real-time process that involves constant monitoring, collection, analysis, aggregation, and dissemination of shared private health information and the resulting discovery of medical knowledge through communities of patients, doctors, researchers, pharmaceuticals and the like.

Biosocial surveillance is considered an application of biosociality (Rabinow 1996) to consumer-marketer surveillance. That is, not only state institutions[23] but also other institutional forces in the market are involved in mutual surveillance, and begin to have a say in the way privacy is negotiated, private health information is shared, and clinical research is conducted. Biosocial surveillance also emphasizes simultaneous, multilevel (patient-patient, patient-physician/researcher, patient-state, patient-pharmaceutical) and real-time gazing among market actors through mediation of a community (as evident in PLM). Therefore, it may not be categorized as either marketers gazing consumers (Foucauldian panopticon[24]) (Foucault 1977) or consumers wanting to be gazed at by marketers (obverse panopticon[25]) (Kozinets et al. 2004b). Consequently, surveillance is institutionalized by a ‘community’ of diverse healthcare actors, and discourses among community actors influence the decisions to share private health information and sustain their interest in the community.

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[23] Governmental efforts to create a systematic and continuous process that involves active data collection, aggregation, analysis, and interpretation of disease related data (that could serve as threat to human health) to achieve early warning, detection, and situational awareness is referred to as biosurveillance, which could be considered a derivative of biopower. Homeland Security Presidential Directive charges the Secretary of Health and Human Services to "establish a national biosurveillance system for human health, with international connectivity where appropriate, that is predicated on State, regional, and community-level capabilities and creates a networked system to allow for two-way information flow between and among Federal, State, and local public health authorities and clinical health care providers" (HSPD-21, paragraph 21, 2008).

24 Foucauldian panopticon here refers to an oppressive disciplinary entity that leads to the internalization of supervision and the resulting self-regulatory behaviors (Foucault 1977).

[25] Kozinets et al. (2004b) coin this term to refer to consumer exhibitionist and narcissistic desires to be gazed at by the marketer.

CHAPTER VIII

CHANGING DYNAMICS OF THE HEALTHCARE MARKET

From State Intervention to Community Intervention & from Privacy to Sharing

In this chapter, in light of the findings discovered as a result of this research, how PLM as a social networking platform in the healthcare market is beginning to initiate a shift from state intervention to community intervention in organizing sharing, generation, and distribution of private patient data, and from privacy to sharing as a form of organizing roles and relations in the current healthcare system will be discussed[26].

The processes of organization, sharing, generation of and access to private health information are also beginning to be controlled by institutions like PLM. Contemporary medicine had long served as a disciplinary entity to maximize our lifespan and normalize our bodies, hence prevent us from death. State institutions and healthcare providers utilized ‘security’ and ‘fear’ as discourses of power in this process (Epstein 2006), particularly as a means to protect patient privacy and increase mortality salience among patients. With the increased use of Internet for acquisition, analysis, aggregation, dissemination, deployment and sharing of private health data and information, healthcare industry and the state established policies (Health Insurance Portability & Accountability Act of 1996) to protect patient privacy. Adopting a ‘hide it or lose it’ perspective concerning online privacy (Weitzner et al. 2008), these policies strictly set boundaries on the flow of patient health records to third parties

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[26] Excerpts from PLM community actors, which are related to all the arguments made in this chapter, are presented in the appendix.

(e.g., insurance companies, employers), increase consumer sensitivity and fear about privacy, and serve as a barrier to research and discovery (Brown 2008). Macro institutions' excessive reliance on secrecy and desire to have control over patient health information (Weitzner et al. 2008) are now beginning to be challenged by a meso level institution (PLM), the foundation of which is based on sharing private health data.

One of the physicians in PLM argues that patients actually had no inherent right to the information healthcare providers keep about them, a reality that is beginning to change with participatory medicine movement (please see appendix for excerpts). S/he argues that participatory medicine will hopefully bring the following benefits: (1) Easier access to the patient's own medical record enables the patient to question and analyze the information in these records to enhance learning about her/his medical conditions (2) Patients can gain the ability to assess misinformation in their records, and accelerate the treatment process enabled through easy access and smooth flow of these records to healthcare providers. Yet, at the same time, this physician also points to the security issues that are likely to rise as a result of easier access to medical records. Nevertheless, for many patients in PLM, getting ready access to their medical records is more important than protecting privacy (see appendix for excerpts from this dialogue).

Similar discussions also arise concerning the practices of privacy versus sharing in the current healthcare system. As also discussed in the forums and blogs of this community, patients in PLM assess the past physician-patient relationship as a top-down relationship, a one-way governing and surveillance by the physician (please see the excerpts from this dialogue in the appendix). Arguments repeatedly made by patients against the past practices of physicians being considered the sole authority and minimal sharing of information among patients and physicians indicate a strong preference for sharing. Patients concur that openness and privacy are much bigger concerns out in the real world when patients and other healthcare actors interact with each other. They argue that physicians generally withheld information that belongs to the patient in order not to burden patient with unnecessary info. Medical records were not forwarded fully. Physicians decided what is important or not when forwarding info to the new providers, which leaves very little room for patient to have control over her/his medical data. Therefore, even privacy is not practiced and not lived up to its doctrines by the ones who advocate it. In fact, in these arguments, patients in PLM draw attention to the incidents of manipulation of patient private data by physicians.

Patients in PLM discuss why privacy rather than sharing is practiced in the current healthcare system (please see excerpts from this dialogue in the appendix). For example, some patients in the community complain about their physicians, who treat them like a number or a piece (patients perceived as isolated symptoms to be treated), not as a whole, an issue that stems from the long dominating paternalistic approach to patient care leaving limited room for partnership. They argue that physician knowledge was generally limited to the literature s/he has read, patients s/he has treated and colleagues s/he has talked to. Physician-patient relationships suffered from a lack of trust and understanding by physicians. In addition, clinical trials would include only a small number of patients and the results would be published in medical journals, hence limiting the number of people who benefit from such results. Along these arguments, patients also add that physicians are eventually limited to their theoretical knowledge and unable to offer real-time, on-demand health as well as real world practical knowledge (e.g., how a patch medication is used). Patients also argue that there existed disconnectedness not only between physicians and patients but also among healthcare providers. Privacy, rather than sharing was being practiced among these actors, a practice also stimulated by state institutions that threatened physicians with loss of license. Consequently, disconnection among these healthcare actors was inevitable. Even pharmaceutical sales reps in PLM stressed their disconnection from the patients they assisted in the current healthcare system. Patients in PLM also point to the ramifications of practicing privacy, which hinders flow of information in healthcare, especially when a patient is incapacitated and needs immediate help. In addition, privacy has been used as a discourse of power by those who have a vested interest in hoarding medical information of the patient and limit access to patient data as well as prediction and evaluation of this data by the patient.

PLM community actors also argue that with the advent of new technologies, the physician is no longer considered the sole source of information, sole conduit of specialist knowledge, and sole authority of treatment. Such advancements also make them become conscious of their existence. As discussed by patients and researchers in PLM community blog, PLM as a social networking application in healthcare was approached critically by some of the influentials in the market based on the premise that these hyperinformed patients engage in guerilla science and self-medication and increase their risk of death through becoming a part of online health communities (Haig 2007). However, PLM enables consumers to gain more control over their personal health data and in management of their health**,** and actively engage in conducting clinical trials. One of the patients in the community suggests that current HIPAA regulations, while well intentioned, keep researchers from connecting the dots to understand what causes life changing diseases (e.g., ALS), hence serves as a stumbling block to discovery and research (See appendix). Through PLM, patients ‘share’ their knowledge and experiences, engage in clinical research with other healthcare actors, and embrace the ‘shared’ world that provides new possibilities of organizing lives.

Community Intervention in Conventional Medicine (e.g., traditional clinical trials)

PLM community actors argue that community intervention by PLM in organization, sharing, generation, and distribution of private health is approached skeptically by influentials in the healthcare market (See excerpts in the appendix). For example, some drug side effects discovered in ALS community through a clinical trial was criticized as not scientific enough. Despite the skepticism about the value of user-generated trials, these clinical trials have been recognized by one of the prestigious journals, Nature Biotechnology[27], and mentioned in the editorial page (p. 953): "For patients with limited life expectancy, the ability to participate in a very rough, low-level clinical study on a new treatment is far more appealing and timely than waiting for clinical data to be published in peer reviewed literature". PLM research is considered an opportunity to design new experimental patient-centered research methods such that the resulting data will be informative, patient-centered, and inclusive.

As observed in the discussions among PLM community actors, issues raised by the conventional medical community that strives to maintain dominance over the medical research process, also relate to the quality of information generated by these user-generated trials (See appendix for excerpts from this dialogue). Their criticism is that such trials lack scientific rigor, can cause detrimental effects on patient lives and shorten their lifespan, and most importantly, exploit patients. Nonetheless, patients in PLM are aware of these problems and argue that similar risks also exist in the current healthcare system. Jayanti and Singh (2010) also call attention to the risks of learning and sharing in online health communities, which could lead to degenerative learning through ill advice from the members of these communities. However, patients in PLM specifically vote for the idea of validating (scientifically and anecdotally)

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[27] Editorial (2008) “Calling All Patients,” Nature Biotechnology, 26, 953.

whatever information they receive from others through several sources and research links. In addition, patients request additional research links or resources to validate claims concerning drugs and treatments made by others in the community, and presentational forms of sharing are practiced by patients and encouraged by the administrators.

Despite criticisms concerning clinical research conducted by PLM community, patients in this community also call attention to the drawbacks of traditional clinical trials. That is, patients have limited access to randomized clinical trials research; clinicians and academics are in full control of whom to choose for trials and what information to make accessible, which caused information to be available to limited group of people. In addition, patients in PLM also argue that traditional clinical trials are perceived as a distant hope and not a real-world solution for many people. They emphasize the importance of fast and real-time clinical trials, particularly for life-changing diseases. They also argue that in contrast to traditional clinical trials that are under the control of clinicians and academics, the use of social networking for clinical trials brings the accessibility to various patients to clinical trials with no set rules/criteria. Additionally, mutual sharing of health information, learning and doing research help patients better understand their conditions and increase their quality of life through making adjustment to their lifestyles, treatments and the like. Patients also become a part of these communities and actively engage in clinical research with the hope that such engagement improves patient-physicians relations outside of the community, as patients become proactive in their care, and accelerates the discovery of cures for life changing diseases.

Furthermore, patient generated clinical trials in PLM may also serve as a potential and unique source of information for traditional clinical research. Body of medical knowledge generated with many patients with diverse profiles may serve as complementary to traditional clinical trials due to their discovery oriented nature and hypothesis generation orientation (Arnquist 2009; Arnst 2008; Johnson 2008). Such clinical trials may also increase the potential for accelerated trials and faster discovery of diagnosis, prognosis and treatment knowledge, and be more cost effective compared to traditional medical research (Sheridan 2008). Patients in PLM are aware of the reliability and validity of patient self-reported data, yet consider their input as a guide to more randomized clinical research. The organization is also in constant search of both technological and community based (quality grading of patients where users earn stars for completing their profile information and keeping their information current) support mechanisms that will ensure the safety and accuracy of real-world patient generated data.

CHAPTER IX

CONCLUSION

[Insert Figure 4 about here]

In this final chapter, potential contributions of this study to theory and practice will be summarized and future research implications will be addressed. The main objective of this netnographic study was to shed light on how business roles and relations are reorganized in the healthcare market through social media/social networking platforms, one of them being PLM. Different social media platforms in healthcare are already on the rise and enable people to have a say in management of their care and monitor their own well-being. Some of these platforms include Microsoft's healthvault and Google health. What makes PLM unique is that it enables a community platform where different healthcare actors share private health data, monitor their and others' well-being, and engage in clinical research in the privacy dominated current healthcare system. Consequently, this community organization as a research context provided the grounds for exploring the impact of social media on organization of business roles and relations between consumers and marketers.

Figure 4, which integrates the findings depicted in other figures, presents PLM as a new market system where we observe a new reorganization of business roles and relations in the dilution of provisioning in healthcare. Such reorganization of business is performed on the basis of sharing. Processes of sharing legitimized in and through this social media platform and the enabling of multidirectional surveillance through intensified connectedness to different market actors also suggest a move away from belongingness and privacy when consumers engage in co-production with other market actors in communities.

Alternative to resistance frameworks in articulating consumer-marketer relations and dialectical constitution of the objectified consumer and the subjectified marketer (dominant in the works of marketing scholars and consumer researchers), this research aimed to explore a market system that presents a more even playing field for market actors as a result of the changes in the expertise system in the healthcare market through social media practices. The results articulate (1) why and how patients participate in the social co-production of medical knowledge and experience, and (2) how the ‘community’ comes to serve as a means for establishing and organizing roles and relations, and as an institutionalization of ‘sharing’ in healthcare. By providing a deeper understanding of how roles and relations are reorganized in and through this social media platform, I draw attention to the dilution of provisioning, collaborative and connective constitution of roles and relations among healthcare actors, and mobilization of actors and governing of relations through the ‘community’.

The results of this research have implications for both sociological theory and marketing theory. From a sociological theory perspective, observation of different roles patients and physicians adopt in this community and how PLM mediates these roles and relations evoke the theoretical linkages to Foucauldian notions of biopower and biopolitical production. As also observed in discussions among actors in PLM, the traditional roles and relations among healthcare actors and the top-down approach to governing relations in the healthcare market reflect the resistant and dialectical (dominant/dominated) aspirations in the conceptual relation between biopower and biopolitical production (Hardt and Negri 2000). Biopower was conceptualized as a modern disciplinary gaze to govern and shape people’s biological lives and maximize their biological lifespan. Biopolitical production involved the resistance to and confrontation with the physician domination through liberatory self-help practices, support groups and knowledge and experience sharing by others other than the influentials in the healthcare market. Inadequacies of physicians in meeting patient needs have prompted patients to seek support from virtual communities and engage in communal information sharing and storytelling. Patients began to seek to satisfy their cognitive, affective, conative and spiritual needs, which are mainly induced by fear and uncertainty about their diseases (Johnson and Ambrose 2006). Biopolitical production was also considered a new way of conceptualizing consumer labor in immaterial terms (Fillion 2005; Hardt and Negri 2004). The inclusion of the networked patients as active participants in medical research and co-producers of new medical knowledge through the sharing of private health data and experiences in this community serves as a potential to initiate the social production of medicine. For this reason, immaterial labor of patients as productive forces in healthcare has come to evolve the unidirectional provisioning, one way of governing relations, and deterministic practices of the macro influentials in the healthcare market (e.g., nation state regulatory practices to protect patient privacy and prevent open sharing, and dominating urges of healthcare providers on patient care).

The license gained by the networked patient in light of transformations observed in technologies and value systems is beginning to put her/him in the role of a validator of her/his and others' well being as well as the physician expert knowledge. This license and expertise is based on patient real-world experiences, and is practiced in presentational forms. Such license in mentoring others, co-producing medical knowledge through active and constructive engagement in medical research (e.g., recruitment of other patients for clinical trials, creation of ideas to use in data generation and design) and reorganizing the 'sharing' of private health data in this community is also beginning to be recognized by the influentials in the healthcare market. As observed in patient-physician collaboration both in the PLM community and outside of the community through PLM, emancipatory and resistant reflections of biopolitical production are now beginning to evolve to a different phase. Reorganization of business roles and relations in healthcare through PLM reflect the move away from alienated and dialectical constitution of healthcare actors to the social and cultural processes of medical knowledge production as well as mutual surveillance of healthcare actors through biosocial communities. That is, the reorganization of business relations and management of patient care are performed by a ‘community’ that gathers diverse market actors for the social co-production of medicine, connects them in multiple ways, and enables a shared participatory medicine founded on dialogue and recognition of patient license by the influentials in the healthcare market.

Findings of how this dialogue is established for the social co-production of medical knowledge and co-creation of medical experience reflect the changing dynamics of provisioning and expertise in healthcare. That is, both patients and physicians come to acknowledge each others’ expertise and become validators of each others’ medical knowledge in non-confrontational forms. Physicians become more receptive to patient license and more willing to adopt an integrated approach (co-analyst) in decision making about patient care, through which proactive and complementary relations are originated. Presentational forms of discourse among actors in this community are adopted for prosocial sharing as a means to find cures for diseases and improve quality of life of patients as a result of mutual learning, increased disease literacy, and mutual monitoring of patient disease progress and treatments. The patient becomes constructive in many aspects of medical knowledge production in this community. S/he becomes an active participant in research and medical knowledge production and in reorganization of sharing and interaction among actors in the community as a means to increase connectivity among actors both inside and outside of the community. PLM's role as a biosocial institution(alization) of new roles and relations among healthcare actors could be comparable to the role of a contemporary pastor, who connects the patient to other healthcare actors to engage in shared decision making about patient care. PLM also engages in mutual governing of relations through non-dominating discourses that constitute actors as free, responsible, licensed and able to negotiate these decisions in new and creative ways.

In this co-mediated market system, the dynamics of pastoring relations to increase sharing and connectedness among actors in healthcare and the resulting co-cultivation of medical knowledge and experience are also investigated. That is, in this reorganization of business roles and governing of relations through the community, how actors relate to each other and maintain their interest and participation and how they legitimize the 'sharing' of private health information were explored. Findings call attention to the forms of sharing that relate actors to each other and influence the legitimation processes of sharing in the community, the community level dynamics of sharing/not sharing (privacy), and reinstitutionalization of surveillance in healthcare through PLM. Most importantly, synergies, which emerged from the negotiations of sharing private health information, that is, how actors arrive at decisions to share or hide their private health data and engage in generation and distribution of medical knowledge, were articulated. From a theoretical vantage point, observations of these processes led us to reconsider the Foucauldian notions of govern-mentality. It could be argued that the processes of sharing versus privacy and generating and distributing medical knowledge in PLM are beginning to initiate a shift from state intervention to community intervention in organizing sharing, generation, and distribution of private patient data. The community also serves as a non-state system of institutionalization of sharing private health information, yet through non-dominating discourses, as opposed to macro organizations (e.g., state, healthcare industry) of sharing private health data through dominating discourses such as fear (e.g., loss of life), loss of ownership of private health data, and the like.

In these processes of negotiating sharing versus privacy, we observe various strategies applied both by patients and the administrators of the community, when actors in the community relate to each other and engage in both self and communal governing of relations. Findings call attention to the complex multilevel and multidirectional relations among healthcare actors in and through PLM community with the dilution of provisioning in healthcare. These multilevel relations and multilateral processes of organizing relations also point to thinking of the community less as a means for belonging (strong commitment and ownership that keep the individual in contact with only the community members when seeking alternative platforms for knowledge gain) and more as a means for connecting (strong desire to share and navigate alternative platforms to enhance learning and disease literacy) with actors both inside and outside of the community. Different levels of connectedness are enabled through the mediation of PLM, which also serve as a potential to increase the mobility and seamless flow of health data among healthcare actors: (1) Patient-to-patient connectedness is increased through intra, inter, and outer communal sharing and learning with, constant monitoring of one's and others' disease progress through surveillance tools, and the resulting enhanced disease literacy and awareness, (2) patient-to-pharmaceutical connectedness is increased through PLM research serving as a yardstick for traditional clinical trials, and pharmaceutical recruitment of patients from PLM community, (3)patient-to-state connectedness is increased through enabling direct reporting of drug side effects to FDA, which also serves as a potential for improved regulation of pharmaceutical practices by the state and the resulting improved medications, (4) patient-to-physician connectedness is increased through recruitment of patients for physician's own trials, personalized medicine through surveillance tools, and mutual encouragement to become a part of PLM. In all of these connections among healthcare actors, patient license to generate and validate medical knowledge and organize sharing and distribution of medical knowledge is beginning to be acknowledged. Patients also have increased access to clinical trials, a process previously dominated and controlled by academics and clinicians.

In light of these findings discussed above, alternative to thinking of govern-mentality as a dominating strategy and a one-way process utilized by corporations to extract value out of free yet enjoyed consumer labor, findings exhibit potentials for the conceptualization of govern-mentality in discursive, communal and productive terms. Govern-mentality is to be considered not as a dominant/dominated dialectical process but as a dialogical process, which I call meridian govern-mentality, reflecting a move away from resistance and emancipatory frameworks to collaborative frameworks in articulating market roles and relations. Inspired by Cova's (2005) thinking of marketing systems in meridian frameworks, meridian govern-mentality draws attention to the co-production of medicine as a dialogical and a social process, and new ways of organizing roles and relations that have the potential to change the dynamics of provisioning and governing of relations in the healthcare market. In addition, meridian govern-mentality includes the consumer perceptions of governing the other and being governed by the other, and the meso level institution(alization)s (rather than macro institutions) that take part in governing of relations among market actors and legitimize sharing of private health data. In PLM, the act of governing presents itself as a multilateral process involving diverse healthcare actors.

Hence, rather than thinking of market relations in terms of the objectified consumer and subjectified marketer, meridian govern-mentality encompasses subjective accounts of both parties and the mutual strategies applied to govern relations for prosocial sharing of private health data. In light of the findings, meridian govern-mentality also points to the discursive constitution of the consumer, yet not only as free but also responsible (self and communal responsibilization used both by the community actors and administrators) and licensed. The system also mobilizes actors for increased sharing of private health data through non-dominating modalities of organizing lives and relations, such as transparency, openness, personalization and (re)signification of diseases through discourses of quality of life, destigmatization and hope. Increased connectedness among healthcare actors in and through the community is established by the mediation of PLM. Through tracking tools, the community serves as a platform for biosocial surveillance in the healthcare market, and enables the constant real-time gazing among consumers, between consumers and marketers (pharmaceutical, healthcare provider, researcher) and between consumers and state institutions as a means to legitimize sharing of private health data and the resulting discovery of cures, new treatments, side effects of medications and the like. In biosocial surveillance, not only the nation state but also other institutions take part in systematic discovery and mutual monitoring of life changing diseases.

The results of this research also have implications for marketing theory. Findings draw attention to how social media is impacting organization of business roles and relations among market actors. This reorganization of business through social media is occurring through three important processes, which enable the maintenance of these new forms of business roles and relations among market actors as they engage in co-production:

(1) Move from unidirectional to multidirectional surveillance in co-production: Previous explorations of consumer-marketer surveillance reflect the either unidirectional gazing of the consumer by the superior marketer and other macro forces (e.g., Nation State) (Foucault 1977) or consumers' increasing desire to be gazed at by these macro forces with increasing willingness to 'be on the screen' (Fırat and Vicdan 2008) and exhibitionistic motives (Kozinets et al. 2004). Social media has in fact contributed to this unidirectional surveillance. However, as social media platforms enable consumers to become active in production processes with organizations, hence blurring the distinction between the organization and the consumer, they also bring about the possibility for multidirectional real-time surveillance including diverse market actors. Although Web 2.0 technologies enable a more even playing field founded on equal grounds between market actors, they may not present themselves as a democratizing force. Nonetheless, the ways in which these technologies are constructed and utilized may indicate levels of democratization (Beer and Burrows 2007), and enabling of multidirectional surveillance is one form of this indication.

(2) Legitimation of sharing versus privacy (e.g., co-production of medical knowledge and experience is performed on the basis of sharing in PLM): Although social media technologies promote openness (Beer and Burrows 2007), privacy dominates the ways consumers relate to each other and marketers, not only in healthcare social media platforms but also in other social networking sites (e.g., Facebook, Myspace). Specifically, access to personally identifiable information without consent (lack of opt-in feature or constant one-way surveillance of the consumer by the marketer without consumer awareness) is not desired and consumers are warned against the risks of excessive sharing on these platforms by state institutions and other privacy advocates. Similar risks and vulnerability also exist in health social networking sites

(e.g., vulnerability to exploitation by marketers and other consumers, exploitation of private health data through fake identities). However, dilution of provisioning by including the consumer in the creation and design of products/services/knowledges/experiences and organization of sharing transcends these concerns. Social media platforms, which enable the consumer increased feelings of license and responsibility in co-production with other market actors, alleviate privacy concerns in favor of pro-social sharing and bring about changes in understandings and values consumers attach to privacy (Beer and Burrows 2007).

(3) Shift in focus from belongingness to connectedness: As previously discussed, social media platforms promote sharing (Belk 2010) and stress the societing and communal aspects of consumer-marketer relations (Cova 2005). When market actors relate to each other and maintain their collaboration among themselves through social media, organization of their roles and relations is formed on the basis of being connected. Social media/social networking technologies (Web 2.0) also enable the origination and continuation of a mindset that increasingly seeks to navigate alternative platforms and sources of knowledge for sharing and connecting to different market actors and forming communities with them. Consumer empowerment through involvement in social media induced co-production processes is in fact constituted with the capability to give away, deliver and distribute available resources of knowledge and experience to others, which also organize and maintain relations in the system (Hemetsberger 2002).

Besides theoretical contributions, this research also has practical implications. Several strategies adopted by patients and other actors in PLM indicate the possibility of how organizations can enable a seamless flow of health data among diverse market actors, and how and at what level they engage actors in the production and distribution processes of medical knowledge. In addition, patients also adopt alternative modalities of managing their and others' care, engage in mutual learning together with other healthcare actors, and co-determine the value of sharing private health data in these processes. The dynamics of legitimizing sharing in the healthcare market, where privacy dominates and organizes relations among actors, also have important implications for organization of business relations in the healthcare industry. Tolerance to alternative sources of medical research and the use of these knowledge sources as a yardstick for further validation of conventional research discoveries become vital, especially for life-changing diseases, which necessitate accelerated research process and faster discovery of treatments. Hence, enabling diverse healthcare actors (e.g., state, pharma, physician, patient, caregiver, researcher) to engage in centralized sharing for decentralized decision making on patient care and conduct clinical research – not just give and receive medical information (anecdotal sharing) – through these Medicine 2.0 communities in the healthcare market could substantially increase collaboration and interoperability among healthcare actors. In addition, encouraging healthcare actors to mentor and lead each other by examples from their lives (presentational sharing) and present alternative modalities of organizing their lives, rather than enforcing each other certain ways of treating ailments, contributes to increased sharing of private health data among community actors. Non-ad presentation of this platform for sharing private health data, availability of real-time help and sharing, anytime sharing (for those who are willing to navigate alternative sources of medical knowledge and participate in the community in the form of lurking, observing, reading and learning new medical knowledge), and formal and informal sharing (for the healing of the body, mind and the soul, and embracing conflict and acceptance simultaneously) also enhance sharing of private health data in this community. All of these characteristics of PLM distinguish this community organization from other social networking sites, which only serve as providers of health information to the patient, enable the patient to engage in sharing at the anecdotal level or exclude the patient (social networking sites for only physician-to-physician knowledge exchange). PLM’s inclusive strategy to create synergy among actors in the community, non-dominating discourses and mid-interventionist and tolerant approach to moderating interactions and sharing in the community, and responsibilization and communal governing strategies to actively engage patients in organizing sharing, production and distribution of medical knowledge and experience also help alleviate concerns for privacy and lead to increased sharing.

This research aimed to provide a deep understanding of a Medicine 2.0 community organization, how it transforms roles and relations and enables a dialogue among healthcare actors, and how it influences the dynamics of the healthcare market as a result. Future research efforts could focus on other social networking platforms in the healthcare market and provide a comparative analysis among these institutions. Despite the increased collaboration for sharing private health data, omnipresent privacy concerns bring about issues related to trust and credibility of these institutions concerning the production of medical knowledge. Future research efforts could also articulate the partnerships between such institutions and the macro institutions (e.g., state and pharmaceutical) and how they design the strategies applied to governing of relations and reducing privacy saliency as they engage others in sharing, generation and distribution of private health data. This research focused predominantly on synergies emerged between healthcare actors, which relate to negotiations of sharing versus privacy. Future research could also focus on other negotiation and decision-making processes that govern relations among actors.

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FIGURE 1: CULTIVATING BIOPOWER-BIOPOLITICAL PRODUCTION-BIOSOCIALITY TRIANGLE IN HEALTHCARE THROUGH PLM

HOW PLM HAS DEVELOPED AND IS FUNCTIONING IN THE HEALTHCARE MARKET?

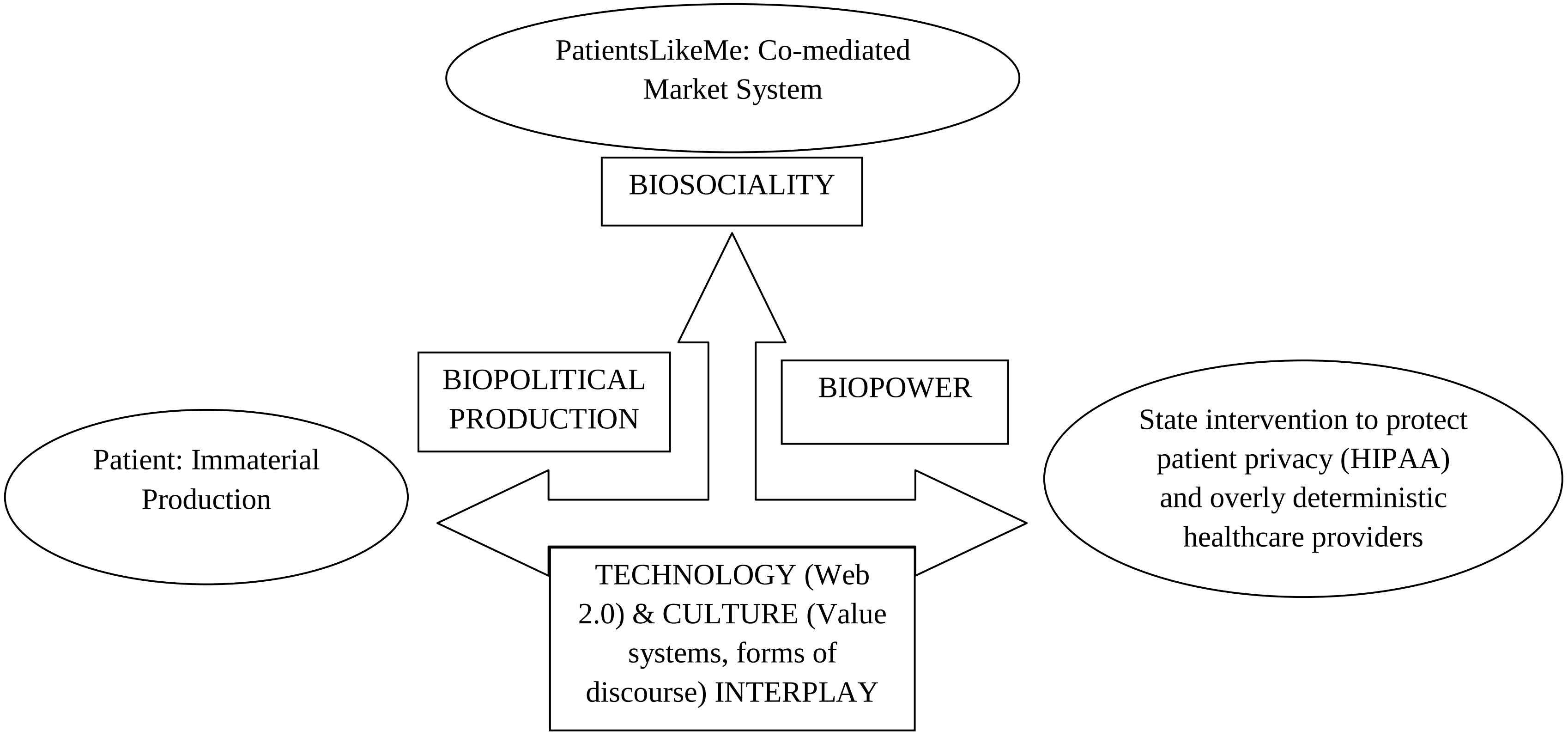
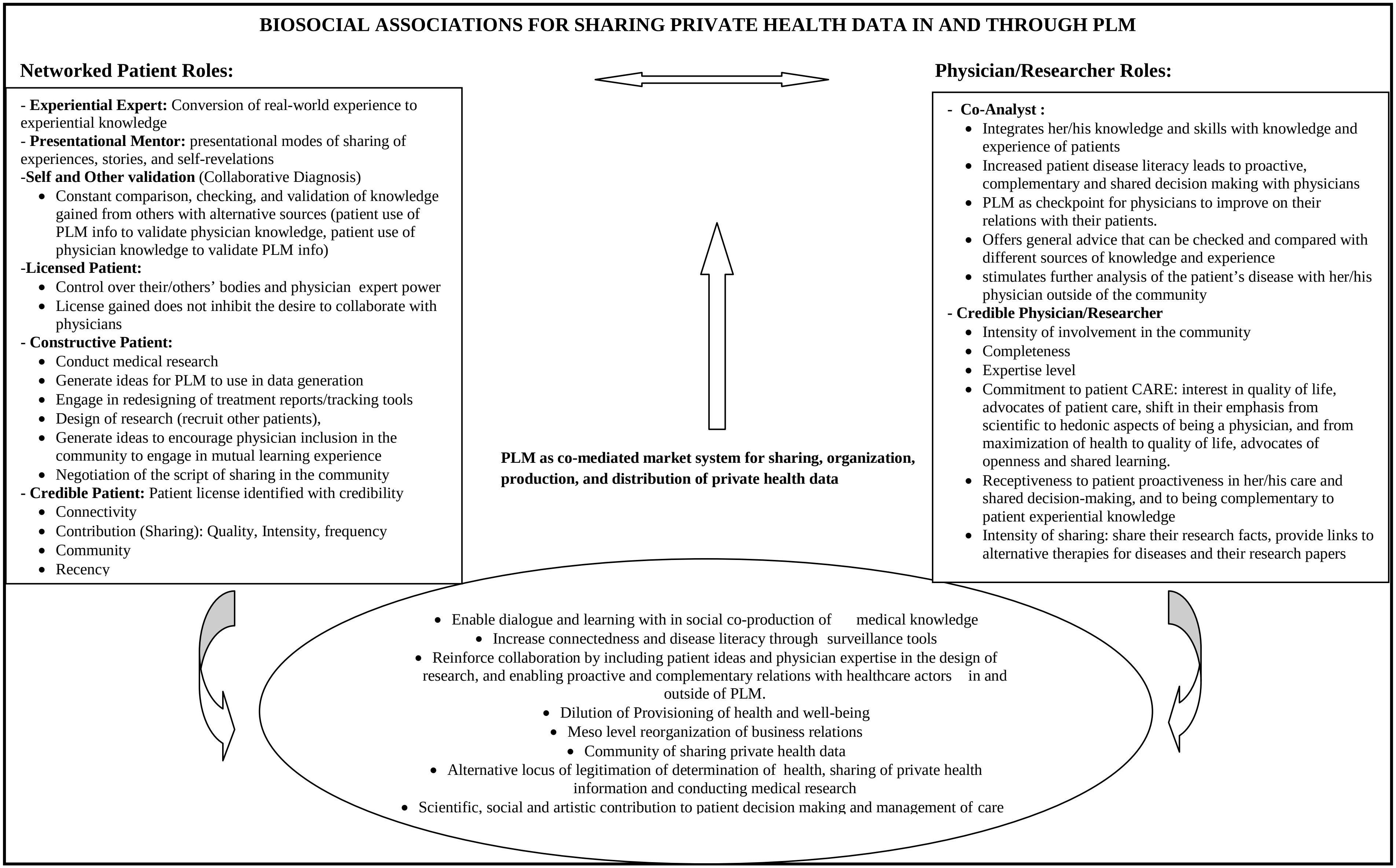


FIGURE 2: CONSTITUENTS OF NEW WAYS OF ORGANIZING ROLES & RELATIONS AMONG HEALTHCARE ACTORS



BIOSOCIAL ASSOCIATIONS FOR SHARING PRIVATE HEALTH DATA IN AND THROUGH PLM

Networked Patient Roles:

- **Experiential Expert:** Conversion of real-world experience to experiential knowledge
- **Presentational Mentor:** presentational modes of sharing of experiences, stories, and self-revelations
-**Self and Other validation** (Collaborative Diagnosis)
  - Constant comparison, checking, and validation of knowledge gained from others with alternative sources (patient use of PLM info to validate physician knowledge, patient use of physician knowledge to validate PLM info)
-**Licensed Patient:**
  - Control over their/others' bodies and physician expert power
  - License gained does not inhibit the desire to collaborate with physicians
- **Constructive Patient:**
  - Conduct medical research
  - Generate ideas for PLM to use in data generation
  - Engage in redesigning of treatment reports/tracking tools
  - Design of research (recruit other patients),
  - Generate ideas to encourage physician inclusion in the community to engage in mutual learning experience
  - Negotiation of the script of sharing in the community
- **Credible Patient:** Patient license identified with credibility
  - Connectivity
  - Contribution (Sharing): Quality, Intensity, frequency
  - Community
  - Recency

Physician/Researcher Roles:

- **Co-Analyst :**
  - Integrates her/his knowledge and skills with knowledge and experience of patients
  - Increased patient disease literacy leads to proactive, complementary and shared decision making with physicians
  - PLM as checkpoint for physicians to improve on their relations with their patients.
  - Offers general advice that can be checked and compared with different sources of knowledge and experience
  - stimulates further analysis of the patient's disease with her/his physician outside of the community
- **Credible Physician/Researcher**
  - Intensity of involvement in the community
  - Completeness
  - Expertise level
  - Commitment to patient CARE: interest in quality of life, advocates of patient care, shift in their emphasis from scientific to hedonic aspects of being a physician, and from maximization of health to quality of life, advocates of openness and shared learning.
  - Receptiveness to patient proactiveness in her/his care and shared decision-making, and to being complementary to patient experiential knowledge
  - Intensity of sharing: share their research facts, provide links to alternative therapies for diseases and their research papers

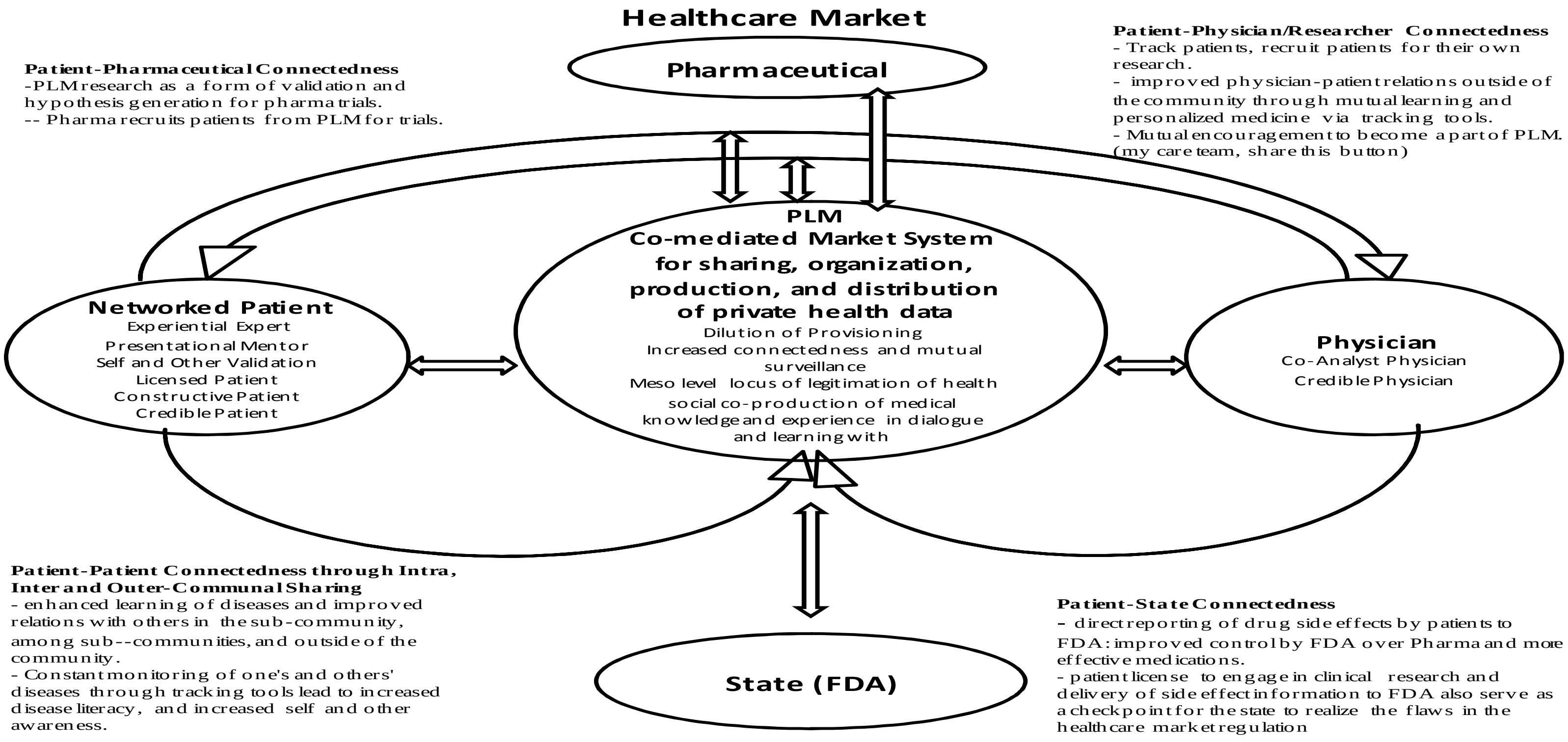
PLM as co-mediated market system for sharing, organization, production, and distribution of private health data

- Enable dialogue and learning with in social co-production of medical knowledge
- Increase connectedness and disease literacy through surveillance tools
- Reinforce collaboration by including patient ideas and physician expertise in the design of research, and enabling proactive and complementary relations with healthcare actors in and outside of PLM.
- Dilution of Provisioning of health and well-being
- Meso level reorganization of business relations
- Community of sharing private health data
- Alternative locus of legitimation of determination of health, sharing of private health information and conducting medical research
- Scientific, social and artistic contribution to patient decision making and management of care

FIGURE 3: FORMS OF SHARING THAT LEGITIMIZE SHARING OF PRIVATE HEALTH DATA IN PLM

- From anecdotal to structured and centralized sharing for decentralized decision making
- Unpolluted sharing: Non-ad Policy
- Real-time Sharing
- Anytime Sharing: Opt to participate versus Opt to detach temporarily
- Formal and Informal Sharing
- Material and Immaterial Sharing
- From Belongingness to Connectedness in the community of sharing: (Navigation)

How Connectedness and Mutual Surveillance Intensified in and through PLM:



Patient-Pharmaceutical Connectedness
-PLM research as a form of validation and hypothesis generation for pharma trials.
-- Pharma recruits patients from PLM for trials.

Patient-Physician/Researcher Connectedness
- Track patients, recruit patients for their own research.
- improved physician-patient relations outside of the community through mutual learning and personalized medicine via tracking tools.
- Mutual encouragement to become a part of PLM. (my care team, share this button)

Patient-Patient Connectedness through Intra, Inter and Outer-Communal Sharing
- enhanced learning of diseases and improved relations with others in the sub-community, among sub--communities, and outside of the community.
- Constant monitoring of one's and others' diseases through tracking tools lead to increased disease literacy, and increased self and other awareness.

Patient-State Connectedness
- direct reporting of drug side effects by patients to FDA: improved control by FDA over Pharma and more effective medications.
- patient license to engage in clinical research and delivery of side effect information to FDA also serve as a checkpoint for the state to realize the flaws in the healthcare market regulation

TABLE 1: MESO (COMMUNITY) LEVEL INSTITUTIONALIZATIONS OF NEGOTIATION AND LEGITIMATION OF SHARING PRIVATE HEALTH INFORMATION

WHY AND HOW OF ‘SHARING’?	WHY AND HOW OF ‘NOT SHARING’?
1- **Community negotiations to alleviate privacy concerns:** Commonality and Uniqueness **2- Private messaging as a temporary detachment** **3- Surveillance and/through connectedness** **4- Giving a face to the disease** **5- Seeking confirmation from others alleviates privacy concern** **6- Discovery of one’s ailment through sharing in PLM** **7- De-identified aggregated sharing** 8- **From Proprietorship to Partnership in Sharing:** Sharing as a right Patients embrace responsibilization of sharing and engaging in organizing and distributing medical health data in collaboration with other healthcare actors. **9- Non-dominating discourses applied by PLM to enhance sharing** a) Openness b) Transparency c) Personalization d) (Re)signifying a Disease (e.g., quality of life, destigmatization, hope) **10- ‘Inclusion’ as a way of energizing the community in sharing** **11- Self and/through Other modulation of sharing private health information** a) (Re)scripting the sharing: Communal Responsibilization: PLM emphasis on patient expertise that could live up to this responsibilization b) The philosophy of light touch moderation: *b1) Tolerance for Difference* *b2) Self-censorship in and for sharing:* “double movement of autonomization and responsibilization” *b3) Aspirational rather than commanding codes of conduct* c) Patient strategies to deal with controversy in forums: *c1) Self through other realization* *c2) Temporary detachment from the community to deal with conflict* *c3) Private messaging as a temporary detachment to deal with conflict* *c4) PLM: practice for real life, and practice a different life*	**1- Cliquing away Inclusion:** Participate to gain more recognition **2- Dealing with trolls or ‘poseurs’: Pay no attention, police, present** **3- Unfit Connection:** *3a) Undiagnosed, Newly Diagnosed, and Less progressive stage patients* More self-revelation, participation, sharing expected form newbies by patients *3b) Oldie-Newbie Distinction* Disease Illiteracy of the newbie Oldie Responsibilization to increase Newbie participation: 1) Responsibilization by both members and the administrators 2) Tolerance for different degrees of commitment (e.g., oldie-newbie, poster-lurker) **4- Patient and Administrator Censorship in Forums** *4a) Patient bashing and bickering as a form of censorship* *4b) Administrator censorship of controversial thread topics* Patient suggestions on member exclusion strategies Responsibilization and communal governing in sharing

FIGURE 4: SOCIAL CO-PRODUCTION OF MEDICINE IN HEALTHCARE IN AND THROUGH PLM

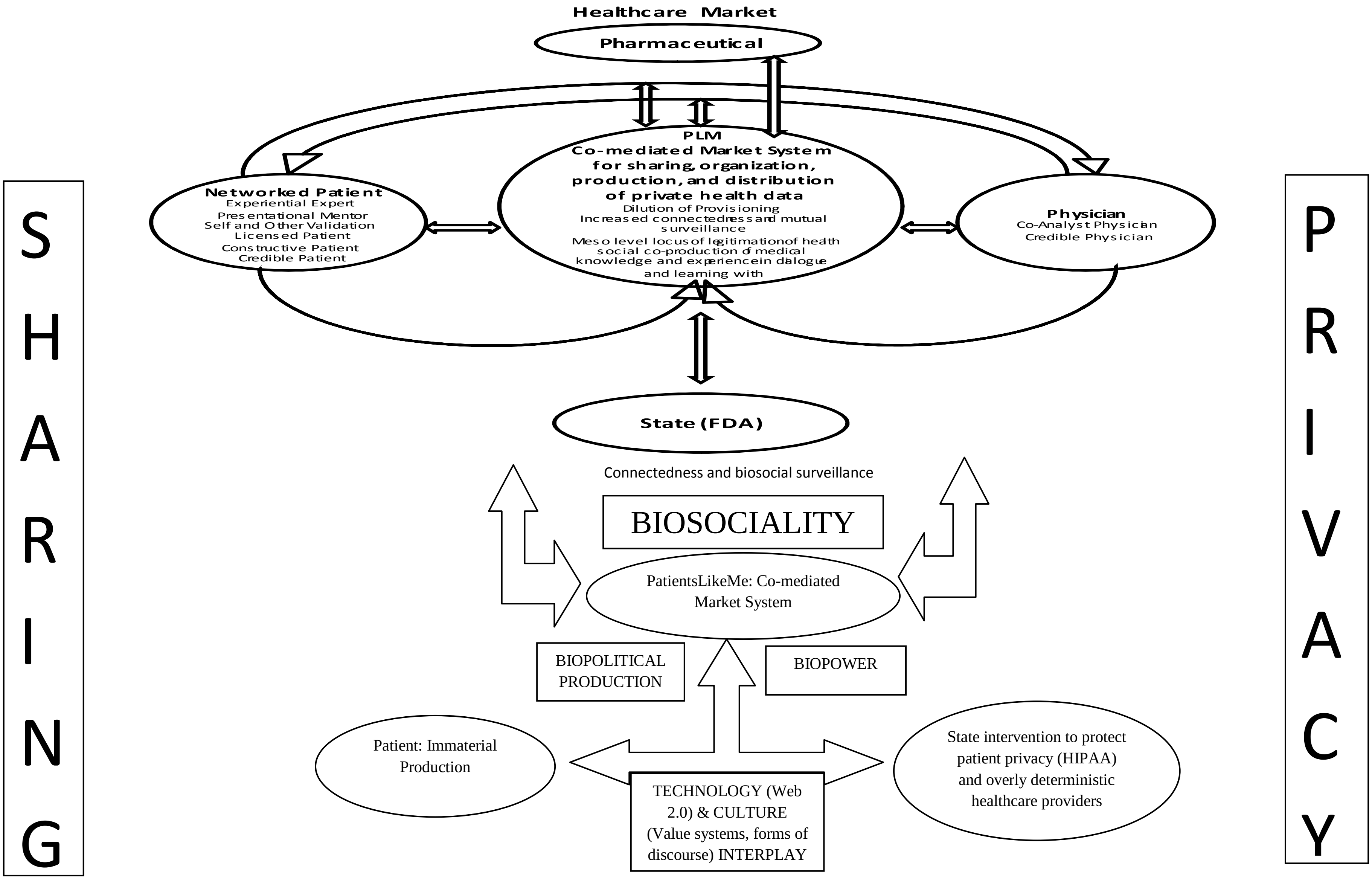


TABLE 2: INFORMANT LIST

PLM Staff	Physician/Reseracher/Caregiver	Patients		
Tim, admin. (admin1)	hukwumaonyeije, physician (phy1)	EdinNJ, Mood (pat1)	Minnie Lee, Fibromyalgia (pat36)	Nacoran, MS (pat71)
Moakes, admin. (admin2)	Rahul K. Parikh, physician (phy2)	dasterne, Mood (pat2)	Mountabora, Mood (pat37)	Pokie, PD (pat72)
Heywood, founder (fdr1)	Nicholas Larocca, physician (phy3)	NewLife, MS (pat3)	Cyprian1, Mood (pat38)	NickAtNite, MS (pat73)
mmassagli, support (sprt1)	Rajnish Mago, physician (phy4)	coyote, MS (pat4)	willowb, MS (pat39)	Nostalgico, Mood (pat74)
JeanaFrost, PLM researcher (res1)	Daniel Wynn, physician (phy5)	Greeneyes, MS (pat5)	Penny Noble, MS (pat40)	Steve S, ALS (pat75)
Emma, support (sprt2)	JaanSidorov, physician (phy6)	0LIMITS, MS (pat6)	Scooterjon, MS (pat41)	The General, Mood (pat76)
PaulWicks, support (sprt3)	docdyer4u, physician (phy7)	humbled1, MS (pat7)	southpaw, MS (pat42)	Eightiesrevival, Mood (pat77)
dwilliams, co-founding executive (fdr2)	lookingforinfo, researcher (res2)	LadyMac, MS (pat8)	lizupatree, MS (pat43)	Sorrel, Mood (pat78)
	squibm, researcher (res3)	jhcamero, MS (pat9)	rain or shine, Mood (pat44)	NewLife, MS (pat79)
	nerdnurse, caregiver, Mood (care1)	bbeegun, MS (pat10)	BantunianPeanut, Mood (pat45)	Sean McNeil, PLM facebook (pat80)
	Ph.D in ALS, PLM blog (res4)	GBTBIM, MS (pat11)	Morgan, MS (pat46)	Dawnabrat, MS (pat81)
		cazza, MS (pat12)	tlc_31, MS (pat47)	syl, MS (pat82)
		barbou2, Mood (pat13)	CharlotteM, MS (pat48)	LadyMac, MS (pat83)
		jdmccarthy, MS (pat14)	jca, MS (pat49)	Chelena, Mood (pat84)
		Angie, MS (pat15)	Bipann, Mood (pat50)	Crysbo, MS (pat85)
		Altostrata, Mood (pat16)	harpgirl, MS (pat51)	PattyD, MS (pat86)
		nuttynova, MS (pat17)	D'awesome MS (pat52)	Nana3, MS (pat87)
		Joy, MS (pat18)	Dennis/Fruebie, MS (pat53)	Appleflower, Mood (pat88)
		little toaster, MS (pat19)	azlily MS (pat54)	Hushpuppy, Mood (pat89)
		Quinn the Eskimo 75, Mood (pat20)	rainydays, MS (pat55)	kykass, Mood (pat90)
		sukey2u2, MS (pat21)	RonaldLear, MS (pat56)	Screamer, Mood (pat91)
		heyden, MS (pat22)	Leddy, MS (pat57)	mouse, MS (pat92)
		Cindy Hiel, MS (pat23)	Connie, MS (pat58)	slinla, MS (pat93)
		mana52, MS (pat24)	gunxgirl, Mood (pat59)	random_nobody_23, Mood (pat94)
		LifeEnergy, MS (pat25)	homeschoolmom, MS (pat60)	Sylvia, MS (pat95)
		OLDDAWG, MS (pat26)	twilightsun, Mood (pat61)	Flowers, MS (pat96)

		Poli, Mood (pat27)	Thekla, MS (pat62)	Shanamarie, Mood (pat97)
		Yipes, Mood (pat28)	narco33gal, MS (pat63)	Tilliedog, MS (pat98)
		Constance Pipperr, PLM blog (pat29)	GothicRosie, MS (pat64)	AlwaysARebel, MS (pat99)
		Shannah, PLM blog (pat30)	Bobmil, MS (pat65)	SueAnne56, MS (pat100)
		Janet Deason, MS (pat31)	sacleveland, MS (pat66)	Amazon, MS (pat101)
		fragiletruth, Mood (pat32)	young-and-poz, HIV (pat67)	
		gardener, MS (pat33)	penny81, MS (pat68)	
		LisaE, MS (pat34)	Kathleen13, MS (pat69)	
		Lilabelle, MS (pat35)	ETS, Mood (pat70)	

APPENDIX

APPENDIX

ADDITIONAL EXCERPTS

HOW PLM HAS DEVELOPED AND IS FUNCTIONING IN THE HEALTHCARE MARKET?

Networked Patient Roles:

Presentational mentor:

dear friend, i understand your anger as everyone else, this place is a comfort for people, i for one to speak, was very angry about ms, but am learning to cope, they say the lord gives you blessings, sometimes the ones you dont want to except, i have learned from this so far, that i moved to fast in life, and would not slow down, i guess it is time to slow down, and live life a little more cautiously than i had thought. my life has changed, but with the help of others, i have learned that it actually has not changed as much as i want to believe. keep your spirits up, keep your faith, and continue to learn how to deal with ms, instead of it dealing with you . ttalktweet (MS community)

Are you feeling better today? I have to turn to mag cit now and then. It's such a relief when you really need it huh. I found an article for you. You've probably read it but it's interesting and tells you more about the swallowing test. Swallowing Disorders and Their Management in Patients with Multiple Sclerosis http://www.nationalmssociety.org/docs/HOM/clinicalbulletin_swallow.pdf... The danger in having an MSer with a swallowing problem swallow a large amount of anything (ie barium) is the possibility of aspiration. I know. I'm a bowl of fun today. :) Was that YOUR extra brain cell I felt floating around in my head this morning?! It was lively. ;) Love ya (Joy, MS community)

I haven't started medication of course and want to know what to expect. Could some of you give me a clue (Goatbeard, mood community)?

Hi Goatbeard. Welcome! Just want to tell you Sorry to hear about all that you are going through. As far as meds go every person is different so I can only tell you how it's been for me. I have had to try several different medications ranging from TERRIBLE to mediocre to may as well been a jelley bean. Still working at it to get the right fit. The most recent cocktail has been so far the best but still with a bit of tweaking here and there. Then again I've only been at it for about 3 years dx BP. Prior to that I was only treated for depression. It has been a prescription roller coaster ride and it can get REALLLLLLY friggin frustrating when I have to make a switch for the umpteempth time. Thats a real pisser. (C_Saw, mood community)

jca, thanks for your suggestions. You might be interested to know that the tone of conversations is quite different on our three different forums; MS, Parkinson's, and ALS. Obviously as ALS is quite rapid (and sadly fatal) there are a lot of people peddling alternative treatments quite aggressively. If people are clearly flogging something or forcing it down people's throats, we would of course step in and take action. However there are a lot of people out there who genuinely believe in what they're doing, whether that's amalgams or diets or LDN or whatever. They're often patients themselves and believe it has made a difference for them; whether it has or not is very hard to establish. But by encouraging people to share their profile data we can start to see if there are any trends there. By arguing with them or making attacks on their beliefs we are unlikely to change their views; if anything our views tend to get more entrenched when we are challenged! So, if someone says they took treatment X and felt better, I wouldn't be all that persuaded by references (which are very difficult to interpret even for a scientist!), but rather by seeing that this person had filled in their profile in detail and we could all see a real difference in their primary outcome measure or symptom severity after taking treatment X. So if they say there's an improvement we could all see the magnitude of it; is it just that their tingling got a bit better? Or have they gone from a wheelchair to doing cartwheels? We can also see if they were taking other treatments at the time that would have contributed to it. Just as a point of policy, we tend to be relatively hands-off with regards to moderation. We wouldn't intervene if someone took a thread off track, but hope that our members would know to start a new thread if things started deviating wildly. Of course, if you ever felt anyone was over-stepping the mark or being unpleasant I hope you'd know you could always come to me or any of PatientsLikeMe team with it over private messages. Paul (PaulWicks support)

Nothing I have written was said it should be a "rule" That is obviously not my position. I think you may have missed my intended goal. Every single one of those are "standards" to every forum I have ever been on. This being a new one, and with many people joining, along with several newbies, this was meant as a reminder for some, and just some helpful tips for others. No one has to follow any of them. For one thing, it is VERY irresponsible to go around touting "cures" unless you can provide back-up that shows the information is valid. There a many a newbie that are so desperate, they will try anything! I cannot see how anyone could disagree with that. Again, these were suggestions that do not have to be followed, however, it we take a few minutes to really think about some of them, we might find them to be very helpful in the scheme of things. (jca, MS community)

I am entirely grateful to this site and to all of the members who are so vulnerable when they share. I can appreciate JCA's experience and knowledge on this issue. And feel she is truly trying to be protective and not limit our sharing per say. But on the other hand, we all have to use our own discretion and choose what we want to read and act on. And if we start throwing up barriers... we could be possibly missing out on some good information. And as Paul (admin.) has mentioned before, it is important that the person sharing has some good credibility by completing their profiles. I mean, I get enough junk email to fill a ocean... someone is always trying to sell something. Last thing i want is to come to a loving friendly safe place like this and have someone trying to sell me something all the time. But if it were presented in a not so pushy way.... I would be open to hearing about it. (KeepingOn, MS community)

There are treatments out there that don’t currently have the scientific data to back them up but do have lots of anecdotal stories in support. LDN is a good example of that. I think it is good to discuss those types of treatments. I DONT have a small mind but I think reasonable boundaries are important. It just takes a little consideration to set some boundaries and look at it from a post-by-post view. One of the most important points I think jca is making (and I TOTALLY agree) is that if there is ZERO scientific data of ANY kind then why would you want it posted here? You're not going to find some secret cure in that, I promise you. When people post this crap and they aren't even willing to do their OWN research then I'm certainly not going to do it for them. Tom, I'm surprised that you are being so antagonistic. No one is trying to 'restrict' anyone's right to post. This is a discussion about requiring SOME iota of DATA to support claims for cures. This is also a forum for supporting other PwMS. At least I thought that was part of the reason for it's creation. (Joy, MS community)

I think we may need a bit of time on this one for people to cool down, reflect on this, and come back to it in a couple of days' time. All that has happened, so far as I can read it, is JCA has started a discussion on what some potential bits of etiquette for the forum might be as a discussion point; not an official rule-list (we're more about principles than commandments!). So far I haven't seen anything that qualify as out-and-out scamming on our forum (thankfully). There are a lot of things people do that don't have scientific studies to back them up, and frankly a lot of the clinical trial data upon which prescription medication is based can be difficult to interpret at best. If clinicians only took action where they had firm evidence they wouldn't do very much! Our position remains that we would only take action if someone was blatantly mis-using the system; e.g. spamming people with private messages about something they were selling. If the situation was ambiguous, e.g. it was from a well-meaning patient, we would send a clear warning message in the first instance. But even if it sounded quite outlandish, I think we would rather leave our members to make their own informed decisions. We are also not in the habit of locking, deleting, or censoring posts. Although it's true that newly diagnosed people may be less experienced with scammers, we hope that our experienced members will be there as a resource to draw upon, and that if people are making outlandish claims then they will be gently challenged to prove what they say. One last thing, the problem with the internet is that it's hard to gauge the emotions behind what is being said (we need to expand our smiley library) so please give people the benefit of the doubt or make allowances for bad days when things heat up!Thanks, Paul (PaulWicks, support)

The goal of patientslikeme is to provide a place for patients to help patients. We provide the place, you all provide the wisdom. Our hope is that people take that responsibility seriously, and not offer bad, or unproven, advice to others. If someone does make a claim that seems out of bounds it is entirely reasonable (and expected!) to ask for proof, and/or to ask if others have any experience with the treatment being discussed. We certainly don't condone or encourage bad advice. That's not patients helping patients, and it's counter to everything we're trying to do. If someone appears to be offering bad or questionable advice ask them to back up their claims, and/or weigh in with your own experience. (Tim, admin)

I guess the thing is this: I am not an MS expert. (and even if I was, an "expert" is only defined in the terms that the experts want it!) So I guess we wouldn't want to be prescriptive on what was/wasn't allowed because MS is such a complex (and little understood) condition, that it's quite likely that by setting rules we'd be discouraging discourse rather than encouraging it. Would setting rules prevent people from posting stuff that's wrong or naive? Sometimes but it would also mean having to come along and tell people off if they broke the rules. And so far we as a team have been managing to be members of our own site without being "moderators" in the traditional sense. Moderators moderate you see, and I've never found that to be much fun! So, the way that's been working pretty well so far is for the community to self-regulate. If people put stuff up that you think is spurious, by all means ask them for the evidence. And like I say, if people are really being naughty then we will take action. (PaulWicks, support)

Self and other validation through collaborative diagnosis:

PLM was also the first site I stumbled upon, how wonderful for me. I have found so much validation, compassion, intelligence, love and support here. I am blessed. Thank you for sharing your story. Moon (moonlight99)

I find in talking to newly dx people they really just want someone to listen to them and validate what they are feeling. I think that is why the site is good. Once they realize they are not alone in what they are going thru they start looking for answers. Cheryl (oknowwhat)

(commenting on a patient leaving PLM due to too much public exposure) I'll miss you. Your input will be missed. The newcomers will have ONE LESS form of validation as to what this disease HONESTLY DOES take (good, bad, or indifferent) because YOU are one of the people who would HONESTLY TELL THEM. JD (0LIMITS)

Licensed Patient:

There is a forum populated with scores of people with ALS (pALS) and their caregivers (cALS). I have learned more about the real world of ALS from this one site than all other doctors, experts, and researchers combined. I am able to ask tough and personal questions on the forum and get dozens of first hand experiences in response. Beyond the forum, everyone has a personal profile that helps track the progress of the disease. Using the same criteria that my neurologist would use, I use simple surveys to measure my specific progression. Far from being only for my personal benefit, there is a team of researchers that feel more like family that review my profile and compare it to thousands of other members to mine the data for clues into the nature of the disease. Current HIPAA regulations, while well intentioned, keep researchers from connecting the dots to understand what causes ALS. PatientsLikeMe is unique in providing a safe way to make public otherwise confidential and unattainable information. (Steve S)

Constructive Patient:

PLM is very good at what they do. Heywood brothers lost their other brother to MS, and are doing all they can to find a cure…Did you look at the Lithium group? It is pretty amazing that they are doing to see if it is a possible cure - or at least a way to stave off MS for another few months. They just rolled out their behavioral silo as well. I do think it is a good way for patients to see what medications others are on, and what has worked for them. Especially newly diagnosed patients who aren't sure what to do for treatment (Alex Sicre)

The site is more than just information and advice. These patients are active participants in their care, generating data about their symptoms, medications and treatments to create a patient experience database. Even if you don’t have these conditions in your life, there’s some interesting stuff over there. (Amy Mercer)

Several patients were already tracking excessive yawning as a symptom on PatientsLikeMe, through our user-added symptom tracker. Already we have published exciting findings from our community. For example, hundreds of ALS patients completed Paul Wick’s survey on Excessive Yawning and the results were published in a psychiatry journal (Acta Psychiatica Scandinavica). Another exciting development in ALS is first real time drug study - on the use of Lithium in ALS. More published and presented research will soon be featured on our blog and in a new section on the site. Each project demonstrates how we, as a community, can conduct research quickly and easily to accelerate the pace of gathering and disseminating new knowledge. Through member participation, we are gathering the information we need to better understand the course and characteristics of ALS. At the same time, we are creating methods to use patient supplied data to discover and evaluate the effects of new possible treatments. (Jeana Frost, Ph.D. PLM Research Scientist)

I think the most powerful combination for making research discoveries is patients coming together en masse, with researchers and doctors joining the collaboration to make sense of the data. This is the biggest promise of Health 2.0 - ultimately reducing suffering for patients using tools that facilitate self-awareness, comparison to others, and aggregating data to better understand and treat disease. Kudos to PatientsLikeMe for taking initiative in this area. May there be many more studies on many more diseases! (Alexandra Carmichael Co-Founder, CureTogether)

"PatientsLikeMe Public Registry" was something that we took over from a patient very early on. One of our patients, Bobby B, was very active in tracking patients online. He had a long list that he did in the forum, and we felt like it was an obvious extension of what we did. In ALS, we allow patients to opt in to a public registry and that is actually the most explicit example of our openness, which is patients are opting in to have their full name, disease state, and some slight details about them open and outside the site, again, in a very explicit opt-in basis.

Clinical signs are no longer so important for a diagnosis, if the MRI shows lesions. I believe this is why today's MS population is mostly relapsing, as reflected by our membership. Most of the symptoms you see in member profiles, are different from studies conducted just 10 years ago, when cognitive and pain issues were largely dismissed in MS. Most neurologist are still overly focused on preventing physical disability, which is what they were trained to do. The most commonly used rating scale (EDSS) is heavily biased towards physical factors and largely based on how far one can walk. (Tom, hjuland)………Very interesting Tom... we'll have to think about how to show that more complex picture graphically and also how we might, as a site, make some of the cognitive (somewhat invisible) issues more visible. (JeanaFrost-support)

I'm tired of the repeat topics, too. But rather than just bitch about it, there's work that has to be done. Clearly, PLM isn't gonna do it for us right now. I know no one wants to hear this, but if we want to have a nice board to write on, we'll all need to get together and "clean up our room" every now and then, 'til PLM hires a maid. It's a question of effort, and a very important question, cause none of us are getting paid, we're all already struggling with our own shit. . . But you have to decide what you get out of this place. Do you need the support? Are you or were you ever getting it here? Have you made good friends here? Would you like to make more? Do you get anything out of sharing what you've learned about mental illness with those in need? How worth it is PLM to you? (Rkaren, mood community)

Marketer Roles:

Co-analyst Physician:

I am sure that your schedule is busy to say the least. Thank you so much for taking the time to CARE about us I want to tell you how admirable I believe it to be for you to come work with us here. I especially want to thank you for accepting my invitation to work with me. I very much appreciate that (Jenn 5420, MS)

Hello, My name is Debra and I would love to have you as part of my team. I am especially interested in your work with clinical trials. Have you ever done any work with Rituxan? I think it is noble that you will take some of your time to help us in our battle with MS (gabelle, MS).

Credible Physician/Researcher:

saralevin (doctor) : i recommend about this Techniques: http://toprelaxationtechniques.blogspot.com/ it's really helped me.

Thank you for the link Saralevin. I have been doing the deep breathing and the focusing on relaxing your body. My PCP gave me these exercises a couple of years ago when my job was stressing me out. I find that both work. I am a little nervous about trying the tense your muscles and relax them. Every time I bend at the knee to crouch down my calf muscles spasm horribly. Not sure that I would want to bring on those muscle spasms.

Sara, It is absolutely wonderful to have you. Welcome to this site. I have enjoyed it very much. Paul Wicks welcomed me to the ALS site last year because there was really nowhere else for me to go. I did love that site. I am one of the rare one's and I am classed as being between two diseases. As a Doctor, perhaps you will understand what I mean. The people here are very astute and have already helped me greatly with lots of suggestions. Good luck here. Hope I did not bore you with "all about me"! (Katiems)

Graham Steel : steelgraham_ms's profile (researcher providing scientific links to patients and some research facts): Graham has several years experience of obtaining and sharing information between researchers and patients - and now Journals. The patient as always, remains at the forefront - always will

If anyone has tried use of magnetic therapies, and had either positive, negative or neutral experiences, would you please contact me, or respond to this post? I've been researching the structural role of lipids in the neural myelin sheath. My immediate goal is to better understand the effects of approaches that affect cell membrane electrical integrity with respect to MS symptoms. Thanks in advance for your help. If you're curious about my work, I have a draft publication Membrane Power. Please feel free to contact me if you think I can help (squibm-researcher)

Dr. Moskowitz is a pioneer in the field of medical genomics, and has been recognized for his groundbreaking treatment of diseases associated with the angiotensin I-converting enzyme, such as chronic renal failure due to hypertension or type II diabetes. Currently, he is developing "kind" chemotherapy--effective but non-toxic orally available drugs for cancer--targeted against the genes that cause cancers. GenoMed is also developing a cancer Healthchip(r) to identify patients at high risk for a particular cancer so that they can undergo serial imaging and surgical resection of the tumor for a cure while it's still small. (from physician profile: David W. Moskowitz, MD- Chairman, Chief Executive Officer, and Chief Medical Officer of GenoMed, Inc.)

Bethany (a physician in PLM), Welcome to PLM, and thank for you help. It is so nice to know that someone with the knowledge that you have really does care... Hugs (Susie sukey2u2)

Medicine 2.0 Community Organizations in between healthcare actors:

You come to realize that you're in a fight for your life...and you get tougher, ask more questions, do more research, and fight for your health. Everyone here on PLM has really helped me to get more proactive with my health care…being informed and educated helps me feel like I'm in control. I feel less anxiety about my symptoms (angel4nettie, MS).

PatientsLikeMe, the leading treatment and outcomes sharing website for people with life-changing diseases, is proud to announce its first scientific poster award. Today, at the 20th anniversary meeting of the British Neuropsychiatry Association (BNPA), Dr. Paul Wicks, resident researcher at PatientsLikeMe.com received the Association’s first prize for the best poster presentation, entitled “Telesocial medicine for neurological disorders: PatientsLikeMe.com”. “This is the first time that PatientsLikeMe.com has been formally presented at an academic conference and it’s great that the site has received the recognition it deserves,” says Dr. Wicks. “Over the two days of the conference I’ve spoken to neurologists, psychiatrists, and patients, all of whom were enthusiastic about the concept and interested in the development of the site as it branches out to include conditions as diverse as ALS/MND, Parkinson's disease, and multiple sclerosis."… (quote taken from community blog)

PatientsLikeMe is excited to have been selected as a FierceHealthIT Health IT Innovator. We are delighted to be given yet another affirmation that our disease-specific communities and treatment and outcome tracking tools have the power to transform the way patients manage their own care. (Heywood, founder)

While PatientsLikeMe has been honored and cited for its innovation in the area of health and medical research, we were thrilled to be recognized directly for our social and artistic value. Central to PatientsLikeMe, and what drew many of us to work here, is our commitment to empower individual patients to become informed, engaged participants in both their own healthcare and in the creation of new scientific knowledge. This prize attests to our contribution in this area. At PatientsLikeMe, as an inter-disciplinary team of researchers, designers, and engineers, we are building a platform for patients to both share and use health data. Our goal is help patients leverage their own experiences to make good decisions and improve outcomes. As a research scientist here, it is exciting to see how our carefully designed tools engage patients to record, reason with and apply data to inform all types of medical decisions (Jeana Frost, Research Scientist at PLM)

FORMS OF SHARING THAT LEGITIMIZE THE 'SHARING' OF PRIVATE HEALTH DATA IN PLM

viii. *Unpolluted sharing:*

PLM is a research site. They hold up their end of the bargain by providing a place to keep track of symptoms and meds, and a place to ask questions about MS stuff, or other stuff. We hold up our end of the bargain by filling out the data on our profiles as completely as possible. That data is used to hopefully find better treatments or possibly new directions in research. Web sites don't run for free. Each organization has to decide how they'll fund the venture. In the case of PLM, they went with data sales, and not medical advertising. I prefer data sales to seeing a line of ads on every page. (gardener, MS community)

We give out far too much info about ourselves in the forum from time to time, but it's just so nice to talk to other people that know what we're experiencing, and maybe learning a new way to deal with the problem. I'd much rather PLM do this than selling advertising all over the site. With the people they have working to keep this site up and running, they have to find some way to generate money. PLM has always been up front with me, and if anything they do can help find a cure for this Monster, then sell it, give it away, whatever they have to do to help us. Mary (greeneyes)

ix. *Real-time Sharing:*

I have been a PLM-er since October 2007 when the PD site was a meer 827 people registered and maybe twenty posting. Now we are a large family of around 1200 and growing by the minute. The difference in this site is we care for each other and know each other's good and bad days and help the best we can. My support team in PLM is always there for me regardless of the time of day and responds back in a flash. Sometimes at 3am it's just me and the (little people) behind the buttons. Those are the best times because you can really vent one on one with someone who cares and knows what your talking about. Sometimes patients need to know someone cares more than the meds to make them better and that's what you get at

Patientslikeme.com... my experience has not only been the finding of knowledge to help me combat Parkinson's on a daily bases but the support of a team I have come to trust and adore. No question I ask is too small to go unanswered and at any time of the day or night someone is there if for nothing else but to listen to me. Had I not become a member of this awesome group I would not know that I was 1 of 50,000 new cases diagnosed each year in the USA and that I am not alone in looking for a cure for this disease for which there is no cure....POKIE (MS community)

x. *Anytime Sharing: Opt to participate versus Opt to detach temporarily*

Several people have told me that a support group would be a good idea. I think that sitting with a bunch of people would make me really uncomfortable. I also think seeing those who were more physically disabled would bother me. I think that just talking on this forum has helped me tremendously. Is this enough? Or should I give a support group a try? I feel pretty comfortable here. Does anyone else go to any other support networks? Ralyn (MS community)

xi. *Formal and Informal Sharing:*

I enjoy both kinds of threads (conflictual and confirmative). It was not my intention originally (that intention was not as healthy) but I was glad after ETS and I revived those threads because I think it brought a lot of things and discussion back to the forum that I did miss. I need both aspects. I enjoy the socializing and sharing with people I identify with - I also need the informative sites. I reach out sometimes. I realize that some people have issues dealing with this balance, but I hope it can all be worked out soon. This community has been a life saver for me as I've said time and time again. (appleflower, mood community)

Mood issues are not all about positive feelings. Sometimes some of us feel down, irritable, irrelevant, sad/ and can experience perspectives that are exactly the opposite. It needs to be safe to express negativity as well as all else. It is important to be valued just as we are, need to be, at a particular time, to being hurtful directly to any one individual, is probably most hurtful to the perpetuator. One needs to think in terms of projection, for the roots of some feelings; towards some people. Negativity really is ok. Without it; we couldn't recognize positivity. Both poles are necessary and real. We must examine it from within, however, and express it, even, as long as we do not hurt another person intentionally.2yo s cannot help that; but adults can THINK and not be hurtful directly to others. The word DIFFERENTIATION (in psychology) comes to mind. (Michala, mood community)

Nyc, got your request. We are working on expanding our treatment section, and will include alternative therapies. Gdarbo and kakijade we hear you about the organization. We're planning on creating categories within the forums to help people find things more quickly. The exact categories are still being discussed but may include humor, personal and off-topic and then research, treatments, symptoms, etc. This is a month or two away, and we'll be sharing our ideas here before we implement them. I believe you'll find that this will really help organize the forums. You'll still be able to get the data view we have now, but then you'll be able to quickly see just the posts about a specific category. Thanks again! Keep them coming. (Tim-admin)

What I do not want to see happen to this site is for admin to strangle the forum to the point that it is only about medical and medicine! It would be like going to one of those wen Dr sites. Just info, no inter communication with others! I personally like the off topics and such! It breaks up the boring monotony of our daily lives dealing with our physical ailments and disabilities! If the in fighting continues at the rate that is been. i can see where that could very well be a reality! Picture our beloved PLM, and all that we could write about on the forum would be a MS related topic or it would be censored! Is that what all of you want? You are heading that way if as a group we cannot conduct ourselves as adults! And treat each other with respect and dignity! I ask that we stop be so dang temperamental and suck it up and act like we all have some common sense! I truly believe we can do it! It will just take work from all of us!..Jason (jcb, MS community)

It seems as though this site is expanding in members at an accelerated pace. I appreciate any effort that is made to continue to keep the small town feeling aI felt the first day I joined. I thought this is Like MAYBERRY for people with MS. I do realize that they are a number of serious topics related to MS. Mountain Boy, Nick, and several other people are constantly seeking to inform the members of the PLM family. Keeping on and company crack me up. I actually appreciate the OT headings. In a way, they are much more personal in nature and I hope it allows individuals to express their in the moment feelings. It seems as though it may have allowed a lot more people an opportunity to open up about their feelings in the moment. Apparently, this site started as a country road and is now a superhighway! If anything, I think they encourage more people to post their feelings in the moment as illustrated in this post itself. Susanna (heyden, MS community)

We agree that this forum is about MS and related issues *and* that people who come here form important relationships. So there needs to be room for both. So we will be creating categories within the forums. We'll talk about what we're going to do before it happens to get your reactions, but expect that in 6-8 weeks. So it may be a bit rocky until then, as we have grown to the point where we should separate out things more, but we can't get it done sooner. All of the discussions at PLM hopefully do help someone in some way. We realize we just need to make it easier for people to find what they need. We'll get there! Remember what one wise soul said in this forum earlier....."If the Internet were high school, PLM would be the cool kids table."(I wouldn't know - do the cool kids fight?)Tim (admin)

IF this site were to be solely narrowed to the focus of multiple sclerosis, then I probably would not be here as long as I have. This has become an outlet for me, something I've needed that was missing in my life. When I was diagnosed, everything around me changed. And it wasn't a good change. There was the new me, and everyone else in my life wondering why I couldn't just go back to being the old me. Here, I can be the new me, and many times, have fun and NOT talk about MS. I personally like that we can talk about all sorts of things. It's fine to separate it out into different forums, but you can't get rid of the "OT" all together. Steph (sacleveland, MS community)

Healing and well-being is not just about taking medications. It involves the body, the mind, and the spirit. Here at PLM people have the chance to work on all three areas…the forums here address this crappy disease called MS with advice on treating the body as well as treating the mind and the spirit of those with the disease. You need all 3 to cope effectively. I learned that back in the '80's when I nearly died. (BigMess, MS community)

forums are a little microcosm of real life and some people are shrinking violets, others are venus flytraps. Or whatever. If we all are going to be so nicey-nice and considerate that it's all warm hugs and sparkly teddy bears, I'll probably quit coming to these forums because I appreciate the edge and get bored by the syrupy shit. (rubie , mood community)

I'm new here, just found this site yesterday, can't even recall how I got here. Must have been through an article in the New York Times (another lifeline, for me). I was drawn in by the data-driven element of PLM's project (appeals to my fact-seeking analytical self). I hate being ill, I hate this illness, and am still fighting back. No history of any 'mood' disorder (hate that term too) until a few years ago, brought on by some terrible events... I just want my life back. Have never joined any online community for anything in the past but was turned around by two amazing blogs in the New York Times in the last two weeks by Dick

Cavett on depression. A revelation to me, both his postings and all the hundreds of moving, courageous comments left by readers. I'll leave the links here as my humble contribution (Kim500, mood community)

i especially hesitate to post threads about making dinner, books, and the like, i worry that everyone thinks or feel that it's not what they're here for, or that it isn't worth replying to since it doesn't really help solve anyone's problem, you know? at the same time though, i feel that discussing the everyday is confirmation that life does go on, and that we are not defined solely on the one most obvious thing we all have in common (b3ck, mood community)

These are very diverse forums, and sometimes there's just nothing on them that you feel involved with. I've gone weeks without posting for that very same reason before. Have you added any threads to your list of favorites? when I'm feeling out of place on the forums, that's where I usually go. it's okay to bring back an old thread that you relate to more. Another solution i find is to go to the profile pages of some of the people I've really connected with here, or who I think talks about interesting things, and see what their most recent posts were, and then leave a reply to them. Sometimes that will resurrect a really interesting thread that has been buried. BantunianPeanut, mood community

xii. *Material and Immaterial Sharing:*

(on a patient comment asking for sharing PLM profits)…Hi Dennis, May I respectfully disagree? In my case, there just aren't enough viable maintenance treatments out there, and if selling my information to a drug company or concerned party will help to alleviate that situation, then I am all for it. For me, it's all about finding viable treatment options, and maybe, though certainly not in my lifetime, a cure, not only for Devic's Neuromyelitis Optica, but for standard MS forms as well. (Grace53a, MS community)

They do have gifts once you are a "3-starer". I have the PLM shirt, but I know there are other things they have as well... (JCA, MS community)

PLM also sponsors patients and other not for profit organizations in their endeavors to increase disease awareness: PLM sponsors Minnie Lee, a member of our fibromyalgia community, and her team as they run 13.1 miles. PLM sponsors the National MS Society New England chapter's 50-mile "MS Challenge Walk" on Cape Cod (Sept. 5-7. 2008). PLM sponsors of the event of National Parkinson's Foundation YOPN Conference in Atlanta, GA on 8/7-8/9/08. (taken from PLM facebook page)

Dennis... while I'm not fond of someone selling my information, blinded or not, PLM does this to keep the site free to those of us who benefit from it. This is no different from the "blind" studies drug companies do and sell their information to others. Did you know that credit card companies do the same thing? Many other places sell your PERSONAL information to others, which is why we get so many telemarketer calls. A lot of people think that you telemarketers get their info from phone books and such, and some do, but more get the info from other companies who benefit themselves by selling it. These companies have NO benefits for us. At least with PLM we have a network where we can "free"ly reach out to each other. Denny, I'm sorry you are discouraged by this, but you have to remember the benefit you've gained from the PLM family. If you leave, you will be sorely missed. Trust that love you believe so strongly in. (NanaBanana54, MS community)

Dennis is gone it seems and I doubt will be posting again here. IMHO some people feel they should be monetarily compensated for anything they do. I my self don’t like "working" for free, lol, but I do like a freebie every now and then...like the t-shirt, I think that’s a great deal. I guess what I am feeling in this thread is that there are some people who would feel better if they got a little something more from

PLM....maybe a mouse pad or USB Christmas tree...LOL...I think its a good topic od discussion since it is apparent there are some members who are needing more from PLM...this might be a good place to post ideas and to just kick the idea around. Its like when you go to buy a car, you dont have to be giving me the best price in the world, just make me think it is! wink wink. Love to all and peace! Philip (MS community)

For better or worse that is how the site is funded otherwise we the people on these pages would have to pay for access to the tools and the forum. Don't think hospitals don't do the very same thing as long as you are not personally identified what's the difference. Its just aggregate information. (numbers) I admit that at first I was concerned that my information may come back to haunt me and it might but I do believe PLM does its very best to maintain our private information as private. We most likely expose ourselves more in the forum section than we should. I have reduced how much I reveal in the forums as I have been bit in the back side by information gleaned from its 309 pages but it is still this is a very good thing. Kelly (OLD DAWG, MS community)

Dennis, how else do you think science/technology advance? I have had MS for a very long time and never have I had the opportunity to speak to people who understand what I am going through. PLM has been such a blessing to me as well as others. I'm sorry you feel the way you do. Best of luck to you whatever you choose to do. Jamie (MySecret, MS community)

PatientsLikeMe has the potential to be a great resource for conditions that potentially could be treated by pharmaceuticals. However, its business model — financial support from drug companies and their ilk — leads it into a conflict of interest. For example, patients desperately need a way to collect reports of adverse effects from medications, a responsibility shirked by the FDA and subverted by the drug companies. Would PatientsLikeMe lend its platform to patient communities that have been harmed by drugs, such as those suffering from antidepressant withdrawal syndrome? It seem unlikely, since documentation of iatrogenic conditions might affect drug sales and, therefore, be frowned upon by PatientsLikeMe’s sponsors. Would PatientsLikeMe lend its platform to tracking remedies that are not profitable for drug companies, such as supplements or exercise? Because of this conflict of interest, PatientsLikeMe may serve some patient communities — those to whom the drug companies might eventually sell drugs — but will ignore others — those who will not be drug company customers. Comment by Altostrata — November 29, 2008 (community blog)

Altostrata , Thank you for your comment. I saw one that you left on our Openness Philosophy post. You are interested in antidepressant withdrawal syndrome. Perhaps it makes sense for you to join the site and add that as a symptom. Then anyone else experiencing it will be able to add it. In addition, we most certainly collect adverse event data and we’re in the process of working with the FDA to send that data to them directly. Our patients’ trust is of utmost importance to us. We are not driven by the whims of pharmaceutical companies. We respond to patient needs first as is discussed in our core values. We believe, however, that pharma companies are investing billions of dollars in many diseases and the patient voice must be heard in order for them to bring better products to market. This is what Openness is all about to PatientsLikeMe. I welcome you to join our Mood Conditions community and find other patients like you. (David Williams, co-founding executive)

Research is what is needed and with a new cutting edge site like PLM guess what they can compound that research faster thanks to al the wonderful members who want to help others. sorry u feel this way dennis and have decided to delete your information where u are no longer a equal participant in cutting edge research...Nicole (feathers4me, MS community)

To All the staff members of PLM I want to say "Thank You so much for caring enough to start these sites." If this is what it takes for drug makers to understand patient needs and reactions to medications I say what can I do to help. I no longer feel like I am living in my own private HELL. Let's all join together and beat these darn diseases even if it means we have to strip down naked and have no modesty. Together is much better than being alone and overwhelmed. Use my information for research and to run this web site so I may receive comfort from others that is priceless......your pal and a Patient like you, Pam (PamsaRN, MS community)

It is here where I learned of a device called "Bio-ness LS-300" It is here where I learned of a drug called "Fampridine-SR" It is here where I learned many, many things about MS. I really can't put a price on what it means for me to keep walking. I don't think all the money in the world could replace what I've learned here. I'm 40. My son is 9. I like to go outside and play w/ him. Money can't buy that. I went to your profile Dennis. And yes......you did remove all your info. I wonder if you had something to teach me. I guess I'll never know. Sad really. I'm always learning here......I hope that maybe you could find something here too. No.........then that would be selfish........wouldn't it. Ya know.....all take......but no give. Be Well. Todd (Smallie, MS community)

Maybe its just me, but I have already received payment for my little bit of information. And it has nothing to do with receiving a PLM T-shirt. My reward was making great friends and meeting patients like me that can relate to what I'm going through. Just a place to talk with fellow ms'ers is enough for me. (KaKiJade, MS community)

WHY DOES EVERYTHING HAVE TO COME DONE TO the ALMIGHTY DOLLAR? how would i have has gotten half the precious information if id not run across this sight? and as someone said above websites don't run themselves for free. I can tell you the information here is very valuable to me. I know that to me this site is no different than having to read and pay for all those idiot self help books and articles(and hope they know what their talking about) why not go directly to the horse's mouth for help? where else am i going to be able to find out with privacy what to do about my terrible constipation?(by the way Miralax worked great thanks) I just feel we all really have many more important things to be concerned about . just my opinion and thats what this site is all about…confused aka robin (confused, MS community)

xiii. *From Belongingness to Connectedness in Sharing:* How Connectedness intensified in/through PLM:

a) Patient-Patient Connectedness through Intra, Inter and Outer-communal sharing:

I found that Montel Williams' book "CLIMBING HIGHER" was the FIRST AND ONLY way (before I found PLM) to explain to others what the pain M.S. brings with it is like, as well as some of the "political B.S." surrounding M.S. is about... at first I wasn't sure if I was offended until I found myself AGREEING (JD-0LIMITS. MS community)

here are a few sites to check out for yourself. i did alot of research before i decided so good luck to all, and i have been 10 months relaspe free YA HOOO... http://www.freewebs.com/crystalangel6267/index.htm, www.ldninfo.org, http://www.lowdosenaltrexone.org/ldn_and_ms.htm, http://skipspharmacy.com
this site might help u aliilte.. it is free and go down to message forum and register. u will find some great articles and real live people stories.. http://www.ldnresearchtrust.org/, http://ldn.proboards3.com/ this is a board that is also free which has great people here also, this one is of the trials going on: http://www.lowdosenaltrexone.org/ldn_trials.htm#ClinicalInProg, this link is to sammyjo on plm and if u

scroll down u will see a pic of sammy joe and vickie she is also here on plm: http://ldners.org/index.htm (jhcamero, MS patient profile)

I love the ability to graph out MS progression and keep track of all my medications and symptoms. This will come in handy for doctor visits. The graphs are also very revealing in that I can track exacerbations and connect the dots. What I love most about PatientsLikeMe though is the feeling of community and a sense of warm and open invitation to everyone. This is a wonderful time to say thank you to the administrators and support folks here. You work so hard and listen so well to our suggestions. Thank you to all the members and caregivers here too. You've made PatientsLikeMe our community. (Joy, MS community)

Support staff (scottlistfield): My name is Scott and I've been working here at PLM on the design of the new Mood Community. I just wanted to tell you that your experience is exactly what we were hoping for, where you discovered something new about your mood by using our tools. I don't know that it provides any direct answers to the big questions in life, but if it changes a little bit how you think about those questions, I for one will be pretty pleased with this site we've built. Thanks so much for sharing your experience. It means a great deal to us who've been toiling away on this.

i am learning more and more. i just looked at my instant moods and i really like how u have it broken down of the days of week and hrs of days of week. it is showing a clear picture already.. does that start over each week or will we be able to keep track of the week and hrs or is it just gone after a week? i really like i am a visual type of gal and if i can see where my bad mood times are it sure helps me to understand why in the evenings it is my not so good times.. gives me something to look at and wonder why and work on. so are we going to be able to see that each week and it keep going week to week and not be wiped out? hope u understand my logic see it is evening time not my good mood time haha...Lee (pdwheels, Mood)

I have learned many, many things, especially the organization of symptoms, which helps me "think" of myself and my MS. It's easier for me to express myself to my doctors and family. (BEBE, MS)

It is intimidating at first to become familiar with PLM, but worth the effort, and they are improving the site continually. Take advantage of this opportunity. It costs nothing but a little of your time, and is one of the best things to do for yourself and those who care for you. My doctor is even impressed.(That is a rarity in itself!) Learn how to organize, keep records, scope out treatments, and research resources all in one place with no discernable strings attached. You need a teeny bit of courage and a computer. (Mammananny, MS)

b) Patient-Physician/Researcher connectedness

I presented my info this week to my neuro and after looking over my doctor printouts and the details, he was very impressed with the info, he kept my papers for my chart which for him meant he was doubly impressed with it's info! So kudos to you and all the staff who make this site sooooo excellent! (D'awesome, MS)

i have taken my dr the doctors sheet and he loved it.. he has even been to PLM and liked all he saw.. everything is right there for him no flipping thru his charts so i take mine every time i go to see him.. but i also agree some drs feel threatened but hey if u did your job right now u would not feel that way.. but living into days society u have to be your patient advocate for you and knowledge is that power.. i always listen to my dr and he does to me but i also realize alot of drs out there would never do that but i have a very open minded dr thank goodness.. (pdwheels, Mood) our focus on capturing the real-world outcomes of patients really sets us apart. By structuring this information in a way that makes it useful for our patients, clinicians, researchers, and industry partners, we’re really making an impact in our current disease communities, and will do the same as we enter new disease areas. We’re also committed to helping patients improve their patient-doctor communication. Our patients can download our “Doctor Visit Sheets,” which detail all of the symptom, treatment and outcome changes that they have entered in our system. This provides doctors and medical professionals with a complete perspective on the patient as a whole, including information not traditionally captured in medical records. The perspective of focusing wholly on the patients’ needs, while improving the patient-clinician interaction and engaging the research community, makes our communities a unique resource in the healthcare industry. (Heywood, founder)

Please help us spread the word about PatientsLikeMe, and invite others to join us. Invite your medical and care team members to join the community. Simply click the Invite button in the MyCareTeam section. Our Tell the World page also includes information sheets and slides about PatientsLikeMe that you can use at your support groups, doctors offices or anywhere you want to tell others about PatientsLikeMe.

Your care team is made up of people who are actively involved in your care. It could be your doctor, a home health worker, a spouse, parent or child. If you want to invite someone to be part of your care team, there should be a button on your profile that allows you to invite people. I notice that you have a doctor on your care team. Did you not invite this person? If not, I think you should be able to remove them from your care team. As far as what they do, the idea is that they be able to be part of our community to share and learn some of the tips and ideas folks share on here. Eventually, we'd like caregivers to be able to connect with other caregivers who might benefit from talking to someone in the same situation. You can see a list of our MS caregivers here (Maureen, admin).

Many doctors had said that they had been invited to join the site by their patients and were curious to find out more. We were able to use our new Google Mapping feature to show them where their local patients were, which had people queuing to see who they knew that was registered on the site! Several researchers were also interested in forming collaborations and we hope to be able to get our users involved in more research over the coming year. (Paul Wicks, PLM support)

Personalization through PLM affects physician-patient connectedness and relations:

PatientsLikeMe is a an example of one component of personalized medicine (by keeping a record of your moods, medications and side effects over time, your doc can see how things are for YOU, rather than operating under the assumption that you will operate exactly like every other patient they've seen (admin PLM)…Imagine knowing every medication, supplement, or device used to treat your disease. Imagine knowing which treatments work for people just like you -- and having the ability to easily connect with those people. That's what makes PatientsLikeMe different. Seeing the disease progression and the treatments that have yielded those outcomes can help patients and physicians employ a more personalized treatment plan. The power of having a community of "patients like me" was demonstrated recently when we had a user whose weight was dropping precipitously, which can accelerate a patient's deterioration in ALS. Because patients track and share their important outcome measures, another patient was able to remind him of the importance of keeping his weight up. (Ben Heywood, founder)

My biggest problem was getting doctors to listen to me when I brought them this material. It was as though even though I could show them 'evidence' of how I reacted to meds, they continued to assume that I would react the same way as other patients. So, while producing more detailed, personalized tracking is helpful, one also needs a doc who is receptive to that same tracking. The greatest payoff would be more good, less bad. In other words, you would identify drugs that worked more quickly AND you would be able to get off drugs that had intolerable side effects. I now have a doc that doesn't hesitate to take me off of something if I say "I can't tolerate this." But, my previous docs always wanted "proof" of my side effects. Personalized medicine might give them that proof. The greatest risk to patients.. doctors keep ignoring you? If you're like me, that kind of stuff is a big trigger for suicidality. If you take the time to carefully plan out what you want to talk about with your doctor and your doctor says that you are "obsessing" over your illness or that your side effects are "all in your head" and may or may not be the result of "thinking too much"... then you might want to kill yourself. I bet that other people will have better answers. I think that SOME doctors are ready to work with patients in this new way. Like my p-doc and my cog therapist. Others might not be so ready... (CharlotteM, mood community)

What are the greatest risks to patients? just a thought and i may be off base here, but as risk goes, i think some patients may be their own worst enemy. for instance...the doctor visit sheet, and mood charts...i try very hard to be completely honest as i answer the survey questions, but i can easily see how i can manipulate the results to convince my doctor to prescribe me certain meds, or diagnose me with something i may feel more comfortable with. sometimes knowing you are being scrutinized, and specifically what about you is being scrutinized can affect you behavior. (i'm sure you guys already know this) what measures can be taken to guard against that, if any? b3ck (mood community)

This article was just posted on the web edition of US News and World Reports. It helps me understand this thread. I summarized and edited it for PLM relevance. "What is personalized medicine? Personalized medicine is about making the treatment as individualized as the disease. It involves identifying... clinical information that allows accurate predictions about a person's susceptibility of developing disease, the course of disease, and its response to treatment. In order for personalized medicine to be used effectively by healthcare providers and their patients, these findings must be translated into precise diagnostic... treatment .... [ed: I guess that's the data base we're creating here at PLM.] Specific advantages that personalized medicine may offer patients and clinicians include: Ability to make more informed medical decisions, Higher probability of desired outcomes thanks to better-targeted therapies, Reduced probability of negative side effects, Focus on prevention and prediction of disease rather than reaction to it, Earlier disease intervention than has been possible in the past" (Bipann, mood community)

c) Patient-Pharmaceutical connectedness through research in PLM

We also have to remember that PLM gets funded from hard data which they collect from our profiles. The forums are just for us to connect and try to help each other. It's difficult to get hard data from a forum. Although it might interest some pharmaceutical manufacturers the things we talk about in here. Give them real life experiences with the medications that they provide for us and perhaps make them better. With less side effects and maybe lose the whole weight gain thing. That could be something to present to drug manufacturers (Ender, Mood)

One of the reasons certain treatments are very expensive is due to the research & development costs in creating them, particularly if there aren't large populations using them. Pharmaceuticals and other drug developers are typically for-profit entities (frankly, because that's the model that tends to work best) and that significant R&D cost must be recouped somehow, or the treatment would never be developed in the first place. This is where PatientsLikeMe comes in. By partnering with us, drug developers (including pharmaceuticals) can potentially optimize their programs. High-quality, highly relevant data is hard to come by. It's not cheap or easy to recruit patients for clinical trials. We have tools and historical data that can save months or years of research time, and we're building a platform where new tools can be created cheaply and quickly -- tools that no one has even conceived of yet. By helping to reduce the cost of drug development in many different ways, PatientsLikeMe can help reduce the cost of drugs. It will probably be

> at least a few years before we've had a noticeable effect, but the general consensus is that it's inevitable. Like I said, I'm not an expert in the area. I'm not sure what makes a pharma "evil", which ones are considered "evil", or why. But I do have confidence that PatientsLikeMe's policy of transparency and patient-centric attitude will make a difference, and will spread throughout the industry like a benevolent virus. If a partnership with a pharmaceutical comes down to compromising on these principles, we will pass on the deal (jeremy, admin)

MESO (COMMUNITY) LEVEL INSTITUTIONALIZATIONS OF NEGOTIATION AND LEGITIMATION OF SHARING PRIVATE HEALTH INFORMATION

Negotiating the 'Sharing' of Private Health Data through the 'Community':

Micro-Level Dynamics of Privacy: Individual (Micro) concern of sharing private health data in PLM: (1) access to identity or revealing of personally identifiable information (social security numbers, mailing addresses etc.) is not wanted:

> I think each person who posts needs to take personal responsibility for what they post -- additionally, when signing up for this site, it's recommended that user names do not include real names (David)

> Do you feel you are putting yourself at risk? HERE, at PLM... NO. The REST OF THE DAY... HELL YES! I'm NOT advertising my FULL NAME, Social Security Number, Medical Record Number, etc. -- I am putting out the INFORMATION that I FEEL is NECESSARY to COMMUNICATE my concerns, issues, etc. -- NO ONE IS HOLDING A GUN TO MY HEAD, and NO ONE is threatening my standing here (as a user) that I MUST PROVIDE EVERY OUNCE OF INFORMATION... so... WHAT'S NOT TO LOVE???? It's the FIRST place in TWENTY YEARS that I've FINALLY found a place to EXHALE over M.S. -- because WE GET IT here. Sharing too much information for comfort? Again -- DO YOU HAVE a GUN???? Are you SWEARING ME IN before I get to post?? Threatening me to BE MORE OPEN??? MORE OUTSPOKEN??? FORCING ME TO TELL YOU EVERY SINGLE DETAIL OF MY COLONOSCOPY OR WOMEN'S WELLNESS EXAMS????? (Girl, YOU KNOW I could go in to DETAIL!!! lmao) No... I DON'T feel like a HELPLESS VICTIM that you're FORCING ME to do ANYTHING against my will AT ALL. What are the benefits? Besides EXHALING for the first time in 20 years?? Besides NOT wanting to BLOW MY OWN HEAD OFF after every single neuro appointment when someone TELLS ME AS A FACT that "M.S. NEVER _______ " and then I LOOK IT UP and find out that IT SURE AS HELL DOES, and here's WHY????? THE BENEFITS????? OHHHHH GIRL -- YOU have NO IDEA -- NO EXAGGERATION -- THIS is the FIRST TIME I can be FEARLESS with my M.S. because IT'S NO LONGER in a position of POWER over ME... I HAVE THE POWER over IT now. While I AM still SCARED, and I MAY be LONELY... I AM NEVER ALONE and that, in itself, IS A PRICELESS GIFT that this place silently leaves behind it. Do they outweigh any perceived risk? Okay... perceived risk -- SOMEONE (let's say... A TROLL... poor bastards... get the crap end of the stick EVERY TIME!) SOMEONE decides that they want to TRY and STEAL the information regarding location, birthdate, etc. -- to "USE AGAINST ME" -- sorry, but the ACTUAL DAY of my birth IS NOT the truth by a few days... the ACTUAL LOCATION is NOT covered if I give you the zip code NEXT DOOR... My last name isn't PERFECT if I sign it with first initial -- NONE OF THIS EFFECTS PLM's usage of my info... the fact that I'm on a LIST of meds -- AND???? MY PHARMACIST IS A LARGER THREAT (ALONG WITH HIS STAFF) TO MY PERSONAL SAFETY AND PRIVACY -- am I worried about PLM???

Ohhhhhhhhh hell no, my sistaah!!! If you have any more questions... any comments... IF Y'all NEED ANYTHING from me AT ALL... you just let me know. If I'm being COMPLETELY HONEST... (and 95% of the time... unless I'm dealing with one of my friends here who I'm TEASING, etc.) If I'm BEING COMPLETELY HONEST... let me just say -- when my computer died... a good friend of mine came to me in TEARS -- she wasn't WORRIED that I didn't have money to fix my computer... SHE WAS WORRIED WHAT I WOULD GO THROUGH WITHOUT ACCESS TO PLM -- because EVERYONE in my life who knows ANYTHING about my struggle with M.S. KNOWS HOW MUCH of a POSITIVE DIFFERENCE this place has made in my journey. (and by the way -- IT WAS A PLM friend who FIXED my computer -- LET'S SEE THEM TWIST THAT! (0LIMITS, MS).

I so much agree Liz, the 'good of the many outweigh the needs of the few' We do take a small risk here but the potential gain is enormous. If our voluntarily posted personal disease history helps stimulates new direction for research and study, that is worth it. I'm sure my grandmother would have been here if it existed in her day----and maybe I'd have better answers now. That said, I would not be excited to post my full name, ss#, or credit card numbers here, that would be foolhardy and it isn't necessary anyway. We can pm each other if we want to be in closer contact. The internet is a lot bigger and potentially unfriendly than most think but most identity theft involves financial info and there sure isn't much of that here! lol! Thekla

(2) employment issues, (fear of losing jobs due to disclosure of private health information),

Even though I use my real picture here, I find it easy to share because of the "anonymity" of the internet. Well, I have my info set to private so that Google can't spider me. (I do contract work for Google. I don't want them getting all of this very personal mental health info in their database!) But for me, it's kinda like going to AA or Weight Watchers... Everyone at the meeting can see who you are, but they have the same problems, so they don't care who you are, what you look like, whatever. Twilightsun, mood community

I would withhold info or not seek care due to privacy concerns. I was thrown into MS and was very forthcoming with everyone, including my former employer. If I had to do it all over again, I would keep my mouth shut, with the exception of telling my family. I like the anonymous nature of PLM. I don't include my full name so I'm comfortable in noting my dx and symptoms. I'm technologically savvy and fully understand the privacy programs from GoogleHealth and Microsoft HealthVault, but I am hesitant to save a personal electronic health record with those programs. I would be open to saving my PHR within a closed system to which only my care team would have access. I would also like the ability to back up that information at home in case I changed docs. Again, I fully understand privacy laws and my rights regarding my health information as it relates to employment/life but I have good reason to not fully trust them yet. (MrsO)

What if my online health info gets around and they find a way to fire me b/c I have MS? While I don't hide my MS, I also don't publicize it. The small hospital where I work was bought by a group of hospitals and we are in the adjustment period. I wouldn't put it past my employer to do something like that. (hummingbird)

what is with the possible manipulation of information online??? Whose going to be responsible for looking after IT?? What happens to the information after I die??? Is my husband/wife going to be able to have access?? How are Doctors going to be prevented from turning down patients?? How are employees of medical institutions going to be protected??? What’s going to happen if the computer crashes???? What is with computer viruses??? What is with costs? who is going to have access?? There really are so many questions that should be answered, although I can’t help getting the feeling that, nobody really feels they can do anything about it, or at least control to what extent it will happen and how! That its inevitable is probable, but I still believe that we should have the right to say who knows what,when,and if about ourselves. It’s about freedom of choice, will and about human dignity! Over to you! (LEDDY, MS)

Thank you all for your insights and opinions. The need to protect oneself from employers, the need to not give doctors an easy out (thanks for that, JD), the need to have control over who sees what - and when - are some of the key issues we all need to understand. Very helpful discussion. Hopefully we can keep it going. We've written about this on our blog this morning too (thorgan, admin).

Why not release all the medical data including sex and age that are vital to how you treat a person and what kind of diseases the person might have. But a personal number could substitute name, social security number, home address and other information that could be used to identify the person when someone other than the person him/herself or the doctor treating him/her is watching the data. In this way you could get all the benefits of free medical data while not getting any privacy issues (Taleg)

OK, so if you are an employer with access to these public records, what are you going to think about an applicant who has a "closed" record? (bebop603)

I was surprised when one of the hospitals I worked at stated in orientation that you can be fired instantly for viewing your own electronic medical records without permission. And they offered no ready, legitimate alternative (man-nurse)

(3) insurance companies having access to patient private health information,

If my health info was online for my health plan, who also happens to be my employer, they could find a reason to let me go. Why should everybody (including all the nurses, lab techs, doctors, and other pharmacists that I work with) be able to see my personal health info? What if I was laid off b/c they found out I had MS and we lost our benefits? ALSO, what if potential employers could easily see your health info and didn't hire you b/c you had MS??? What if I was passed up for a well deserved promotion b/c my health insurance/employer found out I have MS or depression? I used to work for an HMO, and I didn't seek help for a long time for depression b/c I didn't want the health plan or my co-workers to know. What if a prospective health insurance plan saw that you had recently had a brain MRI (but no MS diagnosis) and later said that they wouldn't cover MS b/c it was a pre-existing condition? What if you see a doctor who totally misdiagnoses you. You seek a second opinion, and the new doctor sees what the first one said and decides to agree with them? (this actually happened to me!) Certain patients have a 'reputation' such as being downright crazy. What if that reputation was perpetuated in the electronic health record. Every doctor blows them off and doesn't form their own opinion about the patient or the proper course of treatment. Then the patient dies from a brain tumor (which caused the craziness)?! This happened to my co-worker. (Rachel- hummingbird)

I already know that whatever I say to the doctor is not private. It's protected in the doctor's office but once it goes to the insurance company it's anyone's guess so what's the difference if it's digital- it's already so frustrating. The insurance and pharmaceutical companies can do anything they want with the information once it leaves the doctors office as it is no longer protected under the new privacy laws. (ShopGirl70)

(4) pertinence of information sought for to patient care,

Although there is always a danger of the card falling in to the wrong hands. So the thought of having all medical information available with the use of chip card is frightening. I would have to be convinced of the safety of internet and its accessibility. I would too put conditions that I can decide WHO is allowed access to WHAT information and not that its a free for all party! This is just the point about freedom to choose who we have as a Doctor and who we trust? This is then automatically taken away from us. We lose the right to choose what information WE think is relevant for the Medical problem that we are trying to solve. There are situations that a person can behave irresponsibly and withhold information making a situation dangerous for him or herself, but there are too situations where the information really could interfere with the decision made by a Doctor. there is also a danger of Doctors turning down patients because they have access to information before an appointment and suddenly you won't get one any more. Because you aren't seen as profitable enough. or perhaps too costly. or just because you're a pain in the .... (Leddy)

DEPENDING ON the INFORMATION and WHETHER OR NOT it is PERTINENT to my CARE, I might end up withholding information (if it wasn't ALREADY IN THERE somehow) BECAUSE SOMETIMES docs (mostly M.S. Specialists, by the way... because they're FRUSTRATED that it's NOT easily identified NOR curable) ATTEMPT TO belittle, or minimize the situation AS IF WE'RE HYSTERICS. For example, as an abuse survivor, I WILL NOT tolerate a medical professional trying to MINIMIZE, OR EVEN BLAME, a health issue ON MY PREVIOUS TRAUMA as if the current symptoms are a matter of BRAIN GAMES and aren't anything more than psychosomatic. JD (0LIMITS)

(5) Belief that no privacy in today's world:

I do believe that there is truly no privacy anymore, whether you post info on line or not. The only ones who withhold information are people who have done something illegal. And of course, THAT is the info that may be needed! As a nurse, most people were very anxious to share as much info as possible! They wanted help and did not mind giving it. Leddy pointed out some very interesting ethical issues that are involved today. Thanks Leddy. There is still a problem with "doctor shopping" This is when a patient goes from doctor to doctor to get Rxs. Online infor would help cut down on that. Remember, there is surveillance almost everywhere these days. even parking lots. So, if you think you are so private, just forget it! Big government has already taken over, and you can't reallly change that. So I just stop worrying about it. My medical records are open, wanna see? Just look at PLM!!!!! (Gail-dancingrainbow)

Am I at risk from this site? NO, If I felt that I would not be here. The benefits are amazing and helpful. You only put here what you want to put. Now the privacy issue! I can honestly say name one thing in our society today that is truly private. Unfortunately after 9/11 we have lost all rights to our privacy in one form or another. I almost laugh sometimes when going to hospital for blood draws or whatever and they ask me to sign the privacy paper, because I know they know more about me on that computer screen than I probably do! I figure we are a group of people battling the same thing and some of us have our family members or others who support us here. It is our business what we decide to share. So how anyone can possibly think our privacy is at risk is absolutely absurd!!! Keep up the great work PLM! Ann (lullabyak)

I believe the benefits of participating in a health care system using online records outweigh privacy concerns. What privacy? Given the resources, anyone can find out anything about my background. For a variety of reasons, I am already uninsurable so I feel that I have nothing to lose by sharing all the facts with my doctors. However, I do know people who have avoided diagnosis and treatment in order to keep a black mark off their records. We must, must, must fix our health care system. (Joyce- joycesvoices)

unfortunately, there really isn't enough privacy anymore. I just figure to heck with it. If they really want my info they'll find a way to get it anyways. why withhold info that may help me because of someone possibly finding out about my health issues. just my opinion of course. :) I should add that I'm a stay at home mom at the moment and so I don't have the employment concerns with privacy of med info that others do. (Jackie_D)

The web is a scary place but we cannot feel afraid to be connected to a site that is helpful to those of us with Medical disorders. In today's society most of our privacy has went out the window anyways. I think as

> far as legal issues maybe they should make a law where employers etc., cannot use your open medical records against you in order to do away with your employment status. Ann

> I am new to the website and always skeptical of anything like this. But the benefits far outweigh the perceived negatives. Heck, companies these days are firing employees for not disclosing that they smoke on their medical insurance coverage forms. Eventually, and I hope it's sooner than later, I will have all my medical records with me in some type of media format and this site seems to fit the bill for one aspect of this need. I manage my medications utilizing an excel sheet, manually imputing changes, which is very time consuming. In, my opinion, "Big Brother" is always watching and will always be looking at us. Bob (Bobmil)

(6) stigma and discrimination associated with revealing information about their diseases, stigma associated with body and disease

> I hide because I am a single woman in a small community who is afraid she'll never find someone to love her back, because they will never get beyond a disease who's public face is that of disability. I hide because I want someone to know me without MS before they know me with it, so that I will have a fighting chance. The problem is that there is no me without MS. I am now this complicated package of health and disease and anxiety and triumph. That is who I am. And so I hide, not because I am ashamed of my disease, but because hiding keeps me in control. But the effort to stay in control, takes so much energy and makes me feel like I am completely hidden from the world. In many ways knowing that some of you have the same struggles, gives me a community where I am me. I was hoping that you may be able to share with me some of your feelings about disclosure on a personal level, so that I can learn from you. (VeraH)

> One thing that has given me more freedom is viewing my struggle as being in my control. If I choose to be vulnerable and open myself up completely to others not caring how they respond back, what I gain is a richer fuller life. Yes their are risks, risks of being hurt. However, the times that I am not hurt, what I have gained is priceless. My husband like to quote Nike, "just do it." Step out and be vulnerable, open yourself up, don't hide. You will be hurt, and then you won't, you will be hurt again and then at times not. I agree, though, I like people to know me before knowing I have MS. I am not hiding, but choosing to allow them to see me fully and not distorted by their own misconceptions of MS. But if they should see the MS side of me before seeing me without MS, I would hope they are strong enough to handle that. If they aren't they were not meant to be my friend or my lover (husband.) – Cindy (harpgirl)

> Is there any privacy options when tracking weight or symptoms? Knowing me I could be missing It ! thanks, shelly (shellyjenn)

> I have always kept copies of my medical records and shared pertinent info w/a new doc. However, on many occasions, I have been refused as a patient, doc saying that my case was much too complicated. Imagine if they access to my complete medical file - I'd never find treatment at all! I understand the need, but am hesitant to have everything be an "open book". I agree with others that doctors will try to blame current health issues on past experiences. (cyndi_ Moondance3c)

(7) familial reasons (families cannot relate to their diseases, hence they find more people that can relate to them in this community and empathize, not sympathize, which makes disclosure process easier)

> We all have ms and no one can understand ms and thats all there is to it. No one can understand ms and how you feel, except someone else who has it. I'm always telling my husband when he gives me the think positive, your gonna get better talk......and I get mad and yell I am NOT going to get better! I always tell him "live in my body for a day and tell me how positive you will feel" That usually shuts him up. MS is

so many things and different for each of us…I would invite all members in family to join as caregivers and maybe they will learn from all us on here more of what it’s like (KaKiJade)

It’s not that we don't want help and concern from our families, we would just like to keep that stress from affecting our Loved ones. Coming here to talk with other people living similar paths helps us to feel less alone in this fight. It is a way to connect and be honest with no judgment. To let things out so we can gain strength or come to a better place or understanding for the next fight in the journey we need to deal with. It is not a place to escape our families, it is a place so time with our families can be that. Time with our families and not with the MS ALL THE TIME. Joan (joaniekay47)

My family knows all about PLM. I praise it all the time. They know that it's the one thing that's just for me. I share stories about the people here and the things I've learned. I DON'T share PLM with my family. Now I know I may get some flack for that but that's the way it works for me. I like to know that what I say is private with the folks here. If I want my family to know what I say then I tell them. That way the things I say won't be taken out of context by them. Maybe I'm just having a bad day, you know? I don't let my family read my posts because I don't want them to worry about me. Some days I am depressed but when I come here my friends bring me around and I climb out of it. They remind me that it will be ok. I don't have to be healthy here. I guess what I'm saying is that I'm shielding my family in a way. Or maybe I'm shielding a part of myself. Either way it's a necessary thing for me. Maybe not for all but it is for me. Sylvia (syl)

I think what we worry about getting from family and friends - that we don't find here is pity. No one, no matter how ill, wants pity. Yet despite knowing that, it's the first thing most people automatically react with or at least appear to give or sound as if they are giving. What we do want is empathy - so very different than pity. As folks all struggling with various degrees of similar symptoms - diagnosed or not, we can relate and offer each other the utmost in empathy because we have either been there and done that or know we are most likely to be there soon enough. Often we can even laugh through our shared tears at the most awful of things - something you truly have to live thru to understand deeply. I've told people on here things I would never voice to my husband of 34 years, my best friends, my children, my parents, even my doctors simply because I know deep in my heart and soul I am incapable of making them understand. And yet I tell my husband and friends everything - just differently or on a different level. It's not hiding something, it's another way of communicating because of whom you are communicating with and the subject matter. I hope this make sense. PM me if it doesn't and I'll try to explain it more. I think it's what your Dad - the dear man, a true asset to the PLM community, may be feeling as well. He's a true, good man and father - one to be very proud of - just as he is of you. Floyd please don't leave! We need you, and I believe you need us as well. I understand the break. My prayers go out to you and your family. To Better Health, Jeane (rusty327)

I came on to PLM in April. It was a beacon of light during a very dark time for me. I have grown very close to the members in our forum (MS) We have become like a family. This site is so different from any of the other Medical web sites in that we can share and learn from each other from our experiences. As to the sharing of information. Each person makes that choice for themselves, me I am a pretty open person so I tend to share more of myself for the benefit of others. I made this choice nobody forced that upon me. In the beginning i shared less, but as time went by I shared more. I can choose to share my information with only members or with the public. I want to help researchers find a cure so if sharing this stuff public helps that cause that’s fine. I cannot begin to tell you how much I have gotten out of being apart of this place. This place has become more than a web site it is a family I wouldn’t trade these people for anything . We look out for one another , pray for each other, support each other in ways that some of us never get from our own families . Unless you walk a step in our shoes you can never begin to understand what a blessing this place is, or its worth . Unless you face an illness that the world just doesn't understand and feel the sting of rejection from close friends and family you can never even come close to knowing how it feels to find this place and feel like you are finally home. We are all adults, we know what we are getting into, we have counted the cost. The cost of never finding a cure for these illness is worth a little of my privacy. I am not in this fight alone, I fight with over 7000 members I only pray that one day we can all be heard. My heartfelt thanks to PLM and the people who help run this site. For seeing a need and stepping up to help meet it. The need was the Patients Like Me. (thiagirl)

(8) Physical constrains

One friend who has MS and he begs off of entering in because he says that he can't type well... I have seen many letters that aren't "professionally" written, I use a voice recognition program and therefore I can "type" at about 90 WPM with %95 accuracy, taping or grammatical errors should never be are reason for not being a part of our community.(Jarheaddad56)

(9) Denial, intimidation and fear of disease (e.g., after reading patient stories)

PLM was pretty scary to me at first. When I got out of the hospital in Feb. after being dxed, I knew nothing about MS. I came on here and found out all of the things that could possibly happen to me. The spoon story freaked me out, because I couldn't relate to it at all. I didn't even feel a part of the group because of that for a little while. It sort of assumes that every single person with MS has fatigue issues. After a while I realized that there really isn't any symptom that every single one of us has. It also took a while to realize that even though a lot of things can happen from MS, they aren't happening now and maybe won't ever. You can't go around fearing the worst case scenario. That really stomps your buzz. (AlwaysARebel)

Janet is right about denial. I stayed because I had to get a grip. It is embarrassing to post because I cannot type well or multi- task anymore. I use my computer "ease of access" feature to magnify what I find hard to see. It is never depressing in here, it's depressing "out there". It is taking longer than I had hoped to learn the ropes. It is very fast, so you just click on the things you can do at the time and let the rest go or play catch up later. Everyone has been supportive. Nope...there is no excuse, just a use of free agency issue. Linda (mammananny)

I recommended the site to two friends with MS. They both gave me the same answer. They stay away because they found it depressing hearing about people's progression of MS. One of my friends has had MS for 5 years, the other has been in a wheel chair since 1993. I try to look for the positive in all things, and as you know, you can find it here. (martybets)

A support group such as this one is a double edged sword. On the one hand, it offers sound medical information & you make some good friends here. But on the other, you read all these stories & you know if you're not there already, you will be someday. (MissLily)

while lurking the 1st few days after signing on to here i have to admit that some of the posts scared the crap out of me also. but after continuing to read came to the realization that everyone is different. progression isn't, in most cases, quick. i also realized that there is still life after ms dx even with progression. this all helped me with acceptance of the dx. the wealth of knowledge here is great. all the input. so much to learn from others. all the tips on meds and coping with everyday issues is great for any newbie (if they stick around long enough to get over having the crap scared out of them). if they don't care to post, that's ok. posting isn't everyone's cup of tea. but they can still learn from those who do. thanks to all of you who do post. the input and variety of opinions are what makes this site what it is. (parrothead)

Why and how of ‘SHARING’ private health information in PLM:

1- Community negotiations to alleviate privacy concerns:

I've always had mine set to only let PLM members view my info. I suggest if you don't want your PLM stuff out there that you go into your account settings and check on it. As for the blog of PLM that shows up on mine, Tim asked permission if he could use it and I said yes, I don't have a problem with that. I found more of my name on other sites I've been on than on PLM. Obviously there’s no privacy settings on those sites, like this one. Maybe I should change my name to something like Joe Smith. Yeah, that’s probably so common that no one would know if its me or not! LOL (KaKiJade)

That's why we have the PM option because some things just don't need to be on the internet. And that's why they suggest that we use "usernames" I found PLM when I was researching 4AP and I'm so glad that I found it and there was information available to me right away. I think that using a different username for different forums/chatrooms is a good idea. That helps keep your conversations private to each venue. It does make it harder to remember them though but your own family probably isn't your worry so write up a cheat sheet! How much information is too much is something we have to know and be aware of. Don't post full name, and other truly personal details on an internet forum. But, the sharing of symptoms/treatments under an alias is a HUGE benefit to us, the medical community researching this and other people that are just searching for their own answers. So we don't want to become overly paranoid--knowing that a 35 year old man or woman living in Allentown has ms and lots of bladder problems and intermittent vision difficulties is not a security/privacy risk UNLESS you post a nice clear mugshot and/or your full name. And even then it is only a problem if you are keeping your condition hidden for some reason. A username that is a firstname is even reasonably ok because most people don't have names like "Moon Unit" or "Zowie" that are so incredibly unique! I think we simply need to use the precautions available to us here and not take unreasonable risks but this site is too valuable to lose the sharing and openness that it offers. Biggest thing is have a PLM username and something else for other stuff! Thekla

3- Surveillance and/through connectedness

I like the data aspects of the website. I recall complaining to my doctor that the medication I took for young onset Parkinson's disease was causing me to rapidly lose weight. Because I tracked my weight and medication on PLM, I was able to find a dozen other women my age who had experienced the same side effect. My neurologist, William Stamey, said that he sees value in using the Internet in such a way. He said: "The good part is it's a wonderful yardstick - you can compare yourself against others and gauge how they're doing” (Mary Sontz)

PLM has been a great source of info for me, it's allowed me to learn and take that info and help others learn from my experiences. I let them know that I never worry about my private info as I know you all will protect it and use it where it needs to be for the help of others. I let them know that for many this is the only source of connecting with others that are suffering from the same type of illness. I told them how no two people suffer from the disease the same and therefore no two people react to the meds the same and this is the best place to learn about all of the new things out there working. That PLM is the lifeline for so many homebound people with not just MS but all the diseases that you have here on PLM. Mary (Flowers)

I post my information because it may help someone else, and because there are always questions that I have about the various treatments that I use. Reading what works for others can promote a discussion with your doctor, and may point you in the direction of trying something new. Look at how many people on here are now trying 4-AP. Without the forum, I doubt that more than one or two would be otaking it. Many people seem to have benefited greatly from it, and again it can help to promote a discussion with your doctor about the treatment options available.(gardener)

4- Giving a face to the disease:

I find that the more I learn about HIV the more I want to talk to people about it. I feel it is important for others to know that this can happen to them, too. If nothing else positive comes out of this, at least I know my children have learned something from it. (sapphireblue66, HIV patient profile)

Everyone should share! Even if they don't have a disorder, it really helps to connect people. I love hearing other people's stories and experiences because you know what, we all go through similar things (experiences, thoughts, etc) and we are not that different deep down. Being open about taboo or more private matters breaks down that social barrier. (iame2e, mood)

I've taken the path of maximum self-disclosure because it just makes me feel worse to act a part. And more than that, the more we talk publically about mental illness the more we do to destigmatize it, and help other people feel less alone. Which is one of the reasons I write about my bipolar disorder in my blog at http://www.brokenwhole.com/bipolar.html. One of the things that keeps me going with the writing is the responses I get from other bipolar people who've been through some of the same experiences (Brokenwhole, mood)

In my opinion disclosure is, among other things, a political act which in the long term will counter the stigma and discrimination that many of us feel. My situation now is such that there is no more downside to my disclosure. I think most of the worst things have already happened; and I'm still standing :). Awhile ago I saw an article in New York Times - I'll try to find it and post the link - that talked about the issue of disclosure. I got the impression that some people were militant in their approach. Militancy has worked for other minority groups in the past. Perhaps this is controversial, but in my opinion this is the wrong way to go. There may be some fleeting righteousness self satisfaction but in the long run it's harmful. We need to confront society with the best side of ourselves. Has anybody else that about the politics of mental illness? (Gary715, mood)

I don't mind people learning I have MS. I use it as an opportunity to educate others about this disease. I didn't know anything about it until my suspected diagnosis. (Ame)

Like others, I use it as an opportunity to educate non-MSers about this disease, what it is, and what it's not, and how differently it affects each person. Chris (LifeEnergy)

It is my opinion personal medical issues are up to the individual to tell. I also feel we need to educate the public at large so more can be found out on this ugly illness. By sharing with others you the folks who have the illness may be the ones who finally help the doctors find a cure. It is an individual thing as the illnes affects everyone so differently, but by sharing all please someone work on finding the cause which will bring home the cure. There are so many questions but not enough answers. Sean & I Had a talk on this topic a few nights ago wondering on different things happening to him....Is it the meds   is it the MS   is it the person themselves...on and on we go. Bottom line is we need to keep talking on MS so someday there is a cure for it. momofson (caregiver)

As far as disclosure, I think the pros outweigh the cons there. Ironically, I have a friend (early 40's) who was diagnosed in April this year, about the time my real symptoms started. I didn't know much at all about MS either, so I read up on it on the internet (so I could talk to him about it)...not knowing how soon I could REALLY EMPATHIZE instead of SYMPATHIZE. I don't know if reading up on it helped prepare me enough to be able to be of any help to him..or to help prepare me for the shock when a few months later I received my diagnosis (I don't think ANYTHING can prepare you for that news!). I do know that it has helped me to have him as a friend to be able to talk to and "compare notes." We are both on the same treatment (Rebif), so he has "coached" me and given me a lot of good tips. However, this website has been a wonderful benefit to me as well. You have all described a lot of the same things we all feel/experience. As Barb51 put it you don't "get" MS until you get it. So true! It means so much to be able to read what others are experiencing and to communicate with all of you here. Thanks so much for sharing and for listening. Empathy is understanding the feelings...Sympathy is appearing to feel them at the same time So...we can all sympathize and empathize together (mana52).

7- De-identified aggregated sharing:

Ohhhh no, are they going to sell my e-mail address so I get spam? Maybe it'll at least be something good, and it's not like other websites I have signed up for haven't sold my info before and I've gotten a massive amount of spam from that. Am I worried that they're going to sell my medical information along with my name? Absolutely not in the slightest. They can take the information that is on my page and do with it as they please, I know that they will strip any personal data from it (such as my name) before it leaves their hands. this is a matter of trust. In a sense, the same kind of trust you have anytime you sign up for basically *ANY* website, or anytime you put your name into one of those drawings for a new car/boat/motorcycle at the store. The same kind of trust you have when you go to the grocery store or the mall or the movies and you're trusting that no one will break into your car and steal your identity (Springtyme).

8- From proprietorship to partnership in sharing:

"You would think that your ability to share would be as much your right as speech, but is it? It's not clear that is true in healthcare today, nor is it clear that such a right will be protected tomorrow. Privacy is also a right – a right to not share what you do not want shared. It's a fair and just expectation that the doctors and clinicians you employ to support you in your illness will not share your information without your permission. Today, I fear that privacy has become much more than a right; it has become a goal. When that happens, people begin to find ways to make it difficult to share in the name of privacy. There are some that would take away your right to share because they do not believe you are competent to weigh the risks and benefits of sharing, and make a sound decision. Imagine being forced to sign a document before you email a friend on PatientsLikeMe with a question about a symptom? This could be a possible consequence of ill intentioned privacy legislation. We are working to ensure that sharing is preserved as a right. We know that you share with us, and each other, because you trust that we will do the right thing with that knowledge. At PatientsLikeMe, we are working hard to ensure we earn your trust every step of the way. To do this, we focus our energies on ways to help discover new things about each disease here and support the research system. We do this in the spirit of openness espoused in our Openness Philosophy. We work to be transparent about our business model and our decisions, and try to be accessible to you to answer your questions as you participate in our communities. From our experiences at PatientsLikeMe, we know patients are aware of the issues. They understand and weigh the risks and benefits, and are intelligently making rational choices about where they are comfortable sharing information and how their information will be used to help. If we infringe on this right to share or speak (in the interest of preventing discrimination), we are preventing the flow of information and, by our read, acting contrary to the values on which our country was founded. Privacy is also more than a legal concept, it is also a philosophical concept….We have to begin to work on building a society that allows the variation in human health and the variation in human condition, one that allows people to be philosophically created equal. We need to work on building a society where information is not used to discriminate, but to assist and support and improve. Restricting the flow of information will not advance solving this problem. This is not a simple transformation, but we believe it is inevitable. The major privacy issues are not only about health records, but the invisible trail of "breadcrumbs" we leave behind us day to day in life. Health is not a separate concept. It is an integrated concept and, in an integrated world, we have to decide how to build a society that can handle the reality that not all are healthy. We need to work together to get the most productivity and life from all of us. We believe openness can lead the way to such a society." (James Heywood, co-founder of PLM and chairman)

Patient thoughts on the necessity of sharing as a right, which leads to increased learning that alleviates the fear and uncertainty of life changing diseases:

We endeavor to be completely transparent about being a for-profit company. On our home page, we have a question that asks, How do we make money? We also have FAQs that state specifically that we are a for profit company and how we sell the data. We do share our information with academic and non-profit institutions for free at times. It often depends on the research goals and the hypothesis being tested. In the ALS community we have completed much research and shared data with organizations fully gratis. Research is at the heart of our company and we will continue to work with organizations to promote accelerated research. Because we are small, there's only so much we can do on our own so collaborations are important. You will continue to see more in the coming months. (DWilliams)

It never fails when something comes along to help you deal with the devastation of an illness, someone will throw fit, claim you are being taking advantage of. I am a grown woman I read the disclaimers and still joined. We learn more from each other than we do from the "experts". Unless you have PD you cannot understand the fear or uncertainty we face. Other patients that are brave enough to talk about the side effects of meds help others know they are not losing their minds because they think they see or hear something. They give others comfort and hope when it is needed most. We all need a little bit of hope these days, I'm sure something else will come along for the half empty glass people to complain about and us full glasses will still have PLM to turn to (Kay).

9- Non-dominating discourses applied by the system:

a) Openness:

We fundamentally believe that this sharing of health care information, particularly in the environment that we've created, can lead to greater change in any given disease state. One, on an individual basis for patients from learning from each other in terms of how to manage their disease, how to care with the day-to-day issues, how to deal with stuff that's not always dealt with effectively through the clinical relationship, as well as enhancing the clinical relationship. But we also think that this is one of the ways of breaking through the barriers of health care information in a way that we can create a data set that can be used by industry partners, non-profit researchers to further the knowledge base of any given disease state and hopefully improve treatments; both faster and better treatments over time (Ben Heywood, founder)

We will build a platform that allows patients, doctors and researchers the ability to drill down into all of the data in the system, to each and every data point, so that they can trust that our analysis is based on what really happened. We commit to engaging in an open and productive dialogue about our methods, so we can all learn to do this better – today and tomorrow (James Heywood, co-founder)

PatientsLikeMe is built around the idea that patients can drive their own health outcomes through sharing their health information. This is a movement away from privacy as a paradigm for health management. That being the case, the people who choose to be members have weighed the potential benefits and risks of sharing information and land on the benefits side. (Paul Wicks and David Williams, support)

In this day and age, finding a company that puts morals over the almighty buck is indeed rare. This is why as one of the patients on PLM, I feel safe entrusting them with my medical information. When I first joined and saw what they wanted me to share, I was floored. After one day on the site, I realized why it would benefit me and others to share my information. I'm proud to belong to such a group of wonderful people.

PLM is like coming home, our place where we can feel safe to say what's on our minds. We can talk about the bad and the good. We can laugh together and cry together. And the administrators at PLM make it safe for us to do so! Thank you so much for giving us this gift (greeneyes).

b) Transparency:

for any who want to see all of what is being discussed here: http://www.patientslikeme.com/help/faq/Corporate...if u look top page far right click on HELP and it will take u to pages u can read for yourself first hand.. i read all of this when i first signed up. they are very upfront with everything they do which i am thankful for...if sharing my medications, treatments, symptoms will help than i am all for it.. i have nothing to hide and if just one thing can help others including future others than i will share. same goes with clinical trials but again to learn what works and what does not work and all that information is being shared.. if not for this where would we be today oh my i do not even want to think about that... this information is already being shared by other companies.. every drug u take it is listed and yep recorded and shared between pharmacies...and drug companies.. janet (jhcamero)

As our core values stress transparency, it's always good when members bring our FAQ's to the forefront. Yes, we sell the anonymized information to companies that will use the data to forward research in the disease. We don't want anyone to be surprised by what we do with the data, that's why we have it very clearly stated. Withholding patient data because one does not receive direct compensation is one way to view the situation. In that same vein, would you not take a cure for your disease because you didn't contribute to its discovery? Sharing your data helps others learn from your experience to create better outcomes for all. We believe that the prospect of learning ways to improve your day-to-day quality of life and helping to bring new treatments to market faster is worth having a free platform on which to share data. While we respect everyone's right to participate on PatientsLikeMe (or not--this is why it's free), we believe that we are putting patients squarely on the edge of getting new treatments to market faster by sharing health information. We know this level of sharing and our way of doing so is not right for everyone. And that's OK. Fruebie, just so you know, the door is always open for your return (DWilliams, admin).

We are open with our patients about how and why we sell this data (and specifically what data we sell). They understand this exchange and they're all for it. "Sell, sell, sell" someone recently wrote in a discussion about our business model. Why? Because they know our goal in selling is to help pharmaceuticals companies, medical device companies, healthcare providers, and others in the industry learn more about patients. We're giving those companies the kind of information that can help improve the products/services they're creating for patients. (Ben Heywood, founder)

Dennis, we are very upfront about our business model. It is outlined very clearly in our corporate FAQ, and was referenced in a post last month on our core values. It was also described in the New York Times article about us recently.. 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. Our end goal is improved patient care and quality of life. Tim (administrator)

We have given some anonymous data to several Universities like University of Wisconsin, Harvard University, the NIH, and other research organizations to learn more about what we do. We will be working with the FDA as well to understand how we can inform the Federal Adverse Event database such that we can better monitor the drugs that are approved. We've had research projects that were done internally published in the Acta Scandinavica Psyciatica (as a Letter to the Editor) and just recently had an article about patient-doctor interaction in ALS that appears in the European Journal of Neurology. Just so everyone knows, our research team combs through the data to learn more about these diseases as well. And they're world class at doing what they do. We have revenue partnerships in place, those partners are clearly identified on the site. David (admin)

We NEVER rent or sell personally identifiable information such as email addresses, birth dates, names, pictures, city (not state) without explicit consent for ANY purpose. We include the term "marketing purposes" because many websites sell their email lists for marketing campaigns. We do not. The information that we do sell to our business partners includes patient outcome survey results, treatment information, symptoms, and some forum posts. We de-identify ALL information that we sell to our business partners. We also include in our agreements with partners that they are liable if they try to identify patients based on data. For pharma companies, that particular action is illegal and faces stiff federal penalties. I hope this explanation is sufficient. Feel free to ask any question about our business practices. Transparency is one of our core values and it's important that our members feel comfortable with what we do. To learn more about our business development approach please read our recent blog post on the topic (dwilliams admin)

The information and opinions you all share in the Forum may become 'data', just as the information that you input in the treatment, symptom, and outcomes sections of your profile, or responses you offer in special purpose surveys. All that information remains confidential in any use we make of it, because we do not report it in a way that allows individual responses to be linked to information that could identify the actual respondent. Please let us know if you have other questions. Thanks to all for your interest in PatientsLikeMe Inc. Michael Massagli (mmassagli) Research Scientist (support)

mmassagli, you say-"The information and opinions you all share in the Forum may become 'data', just as the information that you input in the treatment, symptom, and outcomes sections of your profile, or responses you offer in special purpose surveys." Are we to assume that any of the "private" personal email messages sent to other users within this system, are also subject to this "data mining" ? (Fruebie)

I think it might be a bit naive to have the opinion "I have no problem with the whole surveillance thing, it is to protect us, and if you have nothing to hide then you have nothing to worry about..." It leaves you far too vulnerable. That said, nothing PLM has collected on us would be harmful. The forum posts do contain a lot of information which anyone can access and may at some point be used to your detriment, but that is above and beyond what they use for their data collection. We post at our own risk. Julie (MostlySuper)

jca, we (the admins) don't have the ability to read your PM's. As Tim said earlier, the only exception to this is if you mark a private message as Spam, then we get a notification with a copy of the message. That said, all the PM's sent across the site get logged into a database. If we felt we needed to see someone's private messages (because of a threat or some other serious circumstances) we would have to ask the software engineers to dig the message up out of the database. We have not done this to date, but it is possible we could. Hope that clarifies things a bit. (Moakes, admin)

All of us at PatientsLikeMe are very excited that this discussion is going on. We do not want anyone to be surprised and the more we talk about how we are going to make this work the better. We ask that you continue to challenge us to do the right thing. We have great ambitions for putting patients in the center of medicine. There will be many challenges to making that happen and it is only collectively that we can accomplish it. Two questions were raised that I want to specifically answer. The first is about private messages. The short answer is that we do not want to read them and in general do not. Our agreement does allow us to read them and in cases of suggested spam, abuse, or fraud or when members have asked us to we have and will need to continue to do so. In addition we have and will continue to run statistics on the frequency of messages, words used, and the network that the messages go to. We do this so we can both understand the purpose of the messages on average and what we need to do to improve the site for our members. The second question was about the government or someone else subpoenaing the data. As was correctly noted if we were legally able to we would inform the community but we would not be able to delete anything from the system. You should also know that even if you were to delete your data it would remain in our backup servers for some time. Legally we cannot destroy information that has been subpoenaed. Because your trust is a driving value of this company we would as much as was possible fight any attempt to get data that a patient does not want to share but legally we will have to follow the law. For PatientsLikeMe to work we need to continuously earn your trust - this is our first core value. We take your trust very seriously. Please continue to hold our feet to the fire on this. –jamie (founder of PLM)

c) Personalization:

While Facebook is a pure-play social network (and defines the space), we are a personalized medicine platform with social networking components. The differences between our companies explain the differences in business approaches. (dwilliams, admin)

d) (Re)signifying a Disease: (e.g., quality of life, destigmatization, hope)

d1) Quality of life:

I love the honesty, the sense of community, the beautiful and vibrant personalities, and the way we strive to lift each other up here. I learned from this place that being sick does not mean you are weak. That we all have great strength. That we are stronger for our sicknesses. And it helps me accept myself and the skin I'm in. In caring about the people here, I'm also allowed to care about myself. This place has made me healthier, and - for that - I couldn't be more grateful. Rkaren, mood community

<u>Organic way of honoring the death</u> (keeping deceased patient profiles live in the community for other to learn from as well as on PLM facebook page to exhibit deceased patients' videos, creating meaning and substance and continuity in the community: ALS is the community where we have had to deal with death the most. Patients recognize it, they actually let us know when patients pass away, because they tend to know the network, and actually that's an important piece of information we capture and then it becomes part of a patient's profile. They do honor them in an organic way within the community, and I think what's great about what we do is that we provide lasting meaning for that patient's disease. (Ben Heywood, founder)

In memory of Sheila E., one of our ALS members who did this CBS Evening News interview for us last year. (taken from PLM facebook Page, which demonstrated the deceased patients' interview video)

d2) Destigmatization:

sexual relations should be a private matter, but here, anything goes. Not to make light of anyone's situation, but here, we are all battling the same disease and all the party favors that go with it. Sexual dysfunction, loss of ambulation, cognitive problems, they are all the same. It's hard to find someone to talk to about this stuff and here we can have the anonymity of our usernames and profile pictures if we so desire. I have nothing to be bashful about (except maybe a naked picture of me, but that would be scarier for y'all), so if I can talk about my problems with sexual dysfunction and help someone... I'll talk. (NanaBanana54)

d3) Hope and Hope'ing':

PLM Team works so hard to maintain the site. THANK YOU GUYS!!!!!!! It truly is "the lock stitch in the fabric of hope" THANKS AGAIN! Patty...

I answered all the questions and will be able to track my progression, print off this and questions to my ALS doctors and compare what other treatments that work for other PALS. I also learned a lot including my FRS score that when I tried before was never sure I was doing it right. Thank you!!! I know there is no ALS cure at this moment but your site sure brings hope to me. I see many new doors opening up for all of us because of this very unique website, PatientsLikeMe.

The site is outstanding. It has filled in gaps, eased fears, given me medical perspective, and made me feel that I'm not alone. Wish I had more to give, but I certainly appreciate what others have given. PLM is a real community (Yipes, mood)

I'm a fairly new member of the board (within the last week) and I've had 2 very nice contacts so far. I think taking the time to read their Bios and seeing they were well composed and indicated issues similar to mine gave me the confidence to open up a bit and privately message them to inquire about things. I think finding people who will provide you with helpful discussion/feedback/advice is a matter of first looking at their bio and history. If they've taken time and care with that, chances are better that you'll end up with something mutually beneficial. (dock, mood community)

Like many others in the ALS community, I scour the news each day hoping my long-awaited miracle has been discovered. though I've been disappointed countless times, the hope I feel with each new discovery is fresh and just as real as ever before. I'm going to talk to my doctor about lithium, and I encourage everyone to do the same. If your doctor hasn't seen the study, you can download it from the Extra Hands for ALS website here: http://www.extrahands.org/lithiumpaper.pdf. Many thanks to Jamie and everyone at PLM for providing this opportunity for us to talk with each other. (Jack Orchard, community blog)

I want there to be better treatments. If someone uses my data to make a better treatment that helps someone else out in the future so they don't have to go through the hell that I do, then good! What do I have to be afraid of? They don't have my real name, my social security number, my address, or any information about me. They have my email address, but it's my "spam" email address, not my personal one, and it has no attachments to any personal information about me. They're not going to steal my identity or tell prospective employers or health insurance companies about my illness. There are much easier ways for people to do that sort of thing. My mood charts could belong to anyone (BantunianPeanut, Mood).

10- 'Inclusion' as a way of energizing the community in sharing:

Tim, I know y'all will get it worked out and as always you'll willingly consider our input, this by far the most accommodating site of any type I have found. I have all manner of faith in the PLM team. Thank you and the all the people who make this possible (OLD DAWG, MS)

PLM is a great site, and we try to work on a concept of inclusion here, treating others as we'd like to be treated. But even here, too, we have our ugly moments. After a big row not too long ago, some of our former contributors migrated to another site. The good is mixed with the bad everywhere in life. But here, at least, we try to skew the balance in favor of the good - or at least neutral! Glad you found your way here and feel comfortable. There really is enough room for all opinions. Hugs. Liz (Lizupatree)

Diversity (of opinions, personalities, disease stages, rankings-old and new members) increases and energizes people as the site grows: we find those on PLM just as in life that are the same, different, acceptable and maybe sometimes difficult to accept for us.... it's just like outside your front door.... but on the internet. we are brought together by a common thread....we are still different, each and every one of us.....thank goodness....what a bore it would be if we were all the same:) i believe it's well worth it to take all the good we can get from here, the people, the friends and sometimes those who don't care for us.... we will be the better for it....we have to learn and share with each other.... (NewLife)

…Its called growing pains of a web site. People wanna delegate what this site should and shouldn't be. People will argue and disagree. What your failing to realize is every topic, whether the topic is OT or not IS needed here. Everyone is here for a different reason. We all share the same crappy disease that brought us here, sure, but once people get the information they need and give information they want to share, then what? Should we roll over and die, stop posting, what? There is no stupid topic or stupid question. We're all here for different reasons. We're all at different stages in our disease acceptance. We all need different things from coming to PLM. All these different topics help SOMEONE in this terrible disease, and thats all that matters. (KaKiJade)

Perhaps making the PLM Forum Code of Conduct a bit more prominent would help. Perhaps the Code could also be posted on the Help page, which is where I just went to find it again to no avail. And perhaps the Code needs to be expanded to include more specifics about behavior that is to be expected, tolerated, ignored, or not tolerated in conjunction with the new OT Sandbox that's being contemplated. I've been away so much lately that maybe things have changed drastically—what with all the new members (hey y'all!)—but having been around since early days, pretty much everything's been game...as new people sign on, the diversity of opinion will only grow, not shrink. Diversity is good. Diversity is interesting. Diversity is entertaining (patrickm).

There seem to be conflicting ideas about the purpose of PLM, and I suppose also about the expectations that others have placed on PLM. And maybe there are some internet newbies who aren't used to the sometimes rough and tumble feel of an active BBS (don't get me started on old skool BBSers!, I say to myself). If you've ever been in a bar/pub after everybody's had a few beers, then I think that's likely not far off from the general feeling of an active, lively, and inclusive site like this one. Not that people here are typing drunk <ahem>, but that you get comfortable enough to talk about things that you normally wouldn't. And if you haven't been here very long, and thus haven't reached that level of comfort and understanding, then maybe just try to focus on the meat and potatoes MS stuff and tackle the more social aspects little by little at a later time. Like MS, PLM can be quite overwhelming and some folks have more time to spend here than others. And also like RL, some people are more blabby than others…most nuance is stripped away, thus making everything subject to so much projection and inference, there is an added burden—and it applies to both the writer and the reader. As a writer, realize when you are venturing into territory that may offend, and after you've written your post, well, maybe re-read it one extra time and try to put yourself in somebody else's shoes. I'm not saying that you change your opinion or stifle your expression, but there are ways of saying stuff and there are ways of saying stuff…As a reader, realize that what you are reading is a tiny sliver of somebody's opinion on something and it's coming from a tiny sliver of that person. Nobody's entire being is here on PLM. It's a part of us, but you can't fit all of you in any online venture, no matter how much you write and how hard you try. People are just too complex. So rather than recoil and strike (flamethrowing), or recoil and feel wounded, reach out! Clarify! Share! And dig the diversity! Maybe you'll learn something. Maybe you'll teach something. Maybe you'll make a new friend or acquaintance in the form of a person you would never have otherwise met in a million years if you ran into them in RL…The truth probably lies somewhere in between while including both extremes. It's all about empathy. You don't have to understand someone to empathize with them. You just have to be able to see their pain, faith, loss, joy or emptiness and realize for just a second how that might feel and then reflect it back to them. Once you start practicing it, it can be both scary and extremely powerful. As I already said, it's also all about respect. God-doG (patrickm)

Personally, I think most of us are as we present ourselves - people with MI trying to learn how to lead healthy lives in spite of our disease. But some people change details for identity protection; some people add cosmetic changes to make themselves more appealing. Some people are led to create multiple identities because of their serious illness. Some people adopt more than one identity out of boredom, and some people do so just from pure malice. All this doesn't mean we can't develop real, meaningful, lasting friendships (Bipann, Mood).

11- Self and/through ‘Other’ modulation of sharing private information:

a) (Re)scripting the sharing:

We're constantly looking for ways to make the site better, and to provide you with more and easier access to information and other patients. Do you have suggestions for improvements we could make to the site, or new functionality you'd like to see here? We'd love to know, although we may not be able to get to all of the ideas right away. If you have ideas please either share them here, or feel free to email me and I'll make sure the rest of the team gets them (Tim, admin).

Thanks for the pointers. Really good suggestions!! We're beginning to experiment with new designs to organize forum posts for and by each user and making the forum more visible generally. We'll be asking for your input soon!! I'd love to hear more especially about what do you think about sites that have one versus multiple forums (JeanaFrost support)

1 - create a linked hierarchical structure or menu for personal data 2 - the ability to re-categorize items, without deleting and reentry 3 - define the headings 4 - visible reply numbers on the thread (thjuland)

Thanks all for the great ideas. We're going to take a hard look at the forum design and functionality, with the goal of rolling out improvements within the next 6-8 weeks (sooner if possible, but there are some other features we're working on for the site as well, particularly some tools to help new folks figure out how to best make use of the site). Keep the ideas coming, we'll compile them and let you all know what we plan on doing before we make the changes to get more feedback before it's a done deal. We've talked about including doctor and clinic information on the site, and it's something we're planning on doing in the next 2-3 months. Again, thanks for the great ideas - keep them coming! (Tim, admin)

it would be nice if you could reply to an individual post so it wouldn’t be a reply to someone 2 pages later. I used to do site design and might still have the scripts for it... no guarantee that i will find it or it would work tho lol im a space cadet and i don’t know what software this site was made off of (or if its all code, script, base etc etc) (monkeely)

On the subject of updating your symptoms, we're locked in debate right now about how to get that done in the best fashion; I may come back and consult with you shortly! Paul...p.s. Keely, thanks for the offer! We're running Ruby on Rails and some other very trendy "Web 2.0" stuff. I do a bit of internet jiggery-pokery myself but this site is so high-tech I wouldn't know where to start reading the books about where to start! =) (PaulWicks-support)

1. Less popular posts archived after a week of inactivity. 2. Humor/Ponderings tab. 3. Personal experiences: Dr's visits, daily disease drama. etc.4. Strictly research. (gdarbo)

Thanks for the suggestions. Love the forum preview idea! Sitting Pretty, we looked at adding spell check and it would be a big effort, and we've found that most of the browsers have them, although we realize that's not as helpful as you'd like. We'll keep it in mind as we rework the forums. We will update our Help section with more info on acronyms - thanks. And more emoticons.... we're looking! We are always improving the site, preferably in smaller, incremental steps. We try and put out a new set of improvements every two weeks. Most of those changes come from suggestions (or problems) our users provide us, which is why we ask you all to let us know what improvements you'd like to see. Obviously the more specific you can be, the better. We're also working on some larger efforts. We launched a new community last week, the Mood community, for people dealing with depression, anxiety, biopolar disorder, PTSD and related issues. We also launched a prototype Lithium tracking tool for our ALS community. We'll be launching four or five more communities in the next 4-6 weeks, extensions of some of our current communities. Our biggest challenge is how we can help people find information as we have more people joining, and more information being generated. We will be making improvements to the forums and to all of our treatment information and reports. We'll also be adding tools to help people add their own notes to the information they report here. As we work on these larger projects (e.g. the forums) we'll be asking for your help, as we did with Mood. We will be starting work on that in the next two weeks! (Tim, admin).

Script suggestions as a means to facilitate patient physician relations outside: Hi Tim, I think I have emailed you some of the problems that I am having. But, I was thinking about this last night and thought that it would be nice if we had a daily symptom journal. I know we can update our symptoms in our profile, but sometimes all of the symptoms we are having aren't necessarily on there or with a journal, we could be more specific as to what is going on (i.e. bladder problems- can't go or frequency/urgency). I think this would help people at their doctor appointments because if they are like me, they cannot remember yesterday. This can also assist people filing for social security. Just an idea. I think it should be private, like our inbox, and printable so we can take it to the doctor or whatever. I just think it would help a lot especially for people that are on here everyday (Jamie- MySecret).

What about a chat? Something for people who like to be able to actually visit with one another and not share with the whole group. I absolutely love this site. I just think it would be fun for people to be able to visit... especially that late night group! Jamie

Tim, If you haven't heard it enough, THANK YOU!! And the rest of the staff for this site! It has helped connect me to some of the most amazing people across the world even. You have helped to provide support and connection to folks all over fighting this thing called ms. Hopefully we can monitor some of this stuff as adults, and agree to disagree on some issues. I am still looking forward to the opportunity to print off and give out information to widen our world here at PLM. Thank you all again for this family of Love and support that you have provided us with! What would a family be without a little dysfunction?! Lol SPT&Ps! (joaniekay47)

Joan, we now have a way you can easily access PLM info! Check out our new (really new) Tell the World area on the site, which includes one sheet print-outs you can take to support groups, doctor offices etc. !! (Tim, admin)

b) The philosophy of light touch moderation:

We've had a lot of success with a somewhat undermoderated site, and in fact it's something that the patients really appreciate as they look at us relative to other forums where they are overmoderated and feel like their voice is squelched. We have a code of conduct. It's a positive code of conduct about positive engagement in the site, and I think that really does set the tone in terms of what they are using it for. There are a couple of interesting things that have happened just organically. One is about profiles. Patients who speak on the forum and sort of have an aggressive voice on the forum, who don't fill out their profile tend to get pushed by the community to do that, because it becomes a validator of who they are, which is an incredibly powerful part of our model. (Ben Heywood, founder)

b1) Tolerance for Difference

(on patients discussing about those who create feuds since they try to give medical advice): We consciously tolerate much here, in keeping with our philosophy of a light moderation and our belief that this is a member's forum. This is an act of faith on our part. It doesn't always work, and then we get put in the position of peacekeeper or policemen, trying to sort out who said what, to whom, and when. We really don't like being put in that position - no one wins and people get hurt. I think we collectively need to learn how be better at community tolerance and respect. Tolerance means allowing others to have different opinions. You can disagree, and you can share your reasons for that disagreement, but having made your case you leave it at that - you respect the judgment of others to make their own informed decisions. Tolerance may mean turning the other cheek when someone is out of line, or discussing it offline. Respect is acknowledging if you were out of line, and apologizing for it. It is owning what you say and what you do as a member of this community. Respect means not referring to others in derogatory terms, and it means listening when people ask you to consider acting differently. We need to talk about how we make this happen here. I'm open to ideas (Tim, admin)
I agree that we should be able to question, correct, and criticize one another. I guess it's just all in the WAY it's done. It crosses the line when people start taking personal jabs at one another. I don't understand why the topic of LDN has stirred up so much controversy, b/c I've read other posts about other meds where people express their opinions, likes, dislikes, and disagreements all the time. Isn't that a big part of why everyone is here? To learn from one another? No one should resort to personal attacks just b/c you may not agree w/someone. I think we're all intelligent enough to know that just b/c someone preaches about how great a certain med is, that doesn't mean people should drop their DMDs right away and go for something else. Everyone knows none of us are MS specialists, and that people are just stating what has worked for them. If someone states their opinion in an irresponsible manner, then they should be disagreed w/ respectfully (mcgoo, caregiver).

The problem people have is giving medical advice and information that may or may not be true. When someone starts giving false information and people start questioning, thinking they should be on the "cure all" drug, well its just not so. I believe in fairness and constructive disagreements and all that. But will not let someone post the almighty miracle drug that isn't true. And I can say that because, I, along with others have been on LDN for longer than 4 months and seen what we've gotten and what we haven't gotten. There’s just no way to tell and until there is, I don't care what drug it is, no one should start screaming "cure" from the rooftops. Ask me in 10 years and I'll tell you....LOL! There is no cure for ms and may never be in our lifetime. I'm a realist. I quit grasping at straws a while ago. I've learned a lot in my year of diagnoses by reading and listening to what other members here have to say. I have a very open mind. That’s what this site is all about. Everyone should be able to voice their opinion and play nice. I think the problem was the way the telling went. It was more forceful than offering a good experience. There’s a lot of new, scared, and naive people on here and any influence of any drug can swing them towards a decision they might have never considered before and may regret. (And I'm not just talking about LDN) (KaKiJade)

There is no one else here trying, telling anyone to use whatever DMD they are on, just their or they are less of a human for not trying it. As you all know, i post very little here, but to have a person come on here playing neuro and telling me to kick what i am taking to the curb for a med that is not approved by the FDA for MS as yet, and others defending him is way more than i can take. Cliff

Cliff, my thought is that if you don't agree with someone, say so, then let it go. Doesn't mean your voice isn't important, simply means we'll speak our minds and let folks sort things out for themselves. You will always have a place here. Keep speaking your truth. We need to hear all views (tim, admin).

Some people need the hope of a "magical" drug and others don't... People should be making educated discussions about their health care. Educated doesn't mean believing some nutty dude on the internet. It means reading the research yourself and working with your doc. Think for yourself (Ninaf)

I don't think Joe is nutty. I think he's found something that works for him and that's wonderful. Not all of us are so lucky. Those of us who can only take opiate based pain meds cannot take LDN. With as many people as there are on PLM, there are bound to be disagreements, but so many deliberately look for things to flame others about. I've found myself on the end of that, so I try to avoid controversial subjects. I cheer for anyone who finds something that helps their symptoms. I pray for those who are suffering with relapses (like my friend Mary). I try to help where I can, but sometimes I cannot sit idly by while someone gets roasted for their thoughts or experiences. If nothing else... I will stay away from topics like this in the future and concentrate on those who need my help. God Bless, Nana (NanaBanana54)

There are always going to be those who have quick cure schemes but as been said, one has to do their own research and work with their doctors to make one’s life more bearable. If I were smart enough to know what a cure for MS would be, the PLM people would be the first to know! (arlee)

PLM is only as good and as successful as the members are. And everyone has valid information to pass on to someone in need. Maybe we don't always think about the people that do not post at all - for whatever reason they have. They just read and absorb all the information and encouragement that is here for the taking. We might never know the full impact on people that we are not even aware of that are watching and listening to us. "A HOUSE DIVIDED CANNOT STAND" That is what we are here; the PLM family is a house. Dear PLM members, Ignore the bickering for a moment and consider the original point of this thread. Very important information for us all to keep in mind. Respect each other enough to allow differences of opinion. Behave in an honorable manner so as not to incite controversy. Honor copyright laws. Refrain from making defamatory, libelous, threatening, abusive, and hateful remarks. Adhere to the User Agreement and report misuse to PLM administration if we want to reclaim this site for it's original purpose. Thank you. (LisaE)

b3) Aspirational rather than commanding codes of conduct

We don't like hearing that people are leaving the site because of things that were said. We really don’t like having bad feelings in the community, and the sense that people are not feeling welcome here, or are feeling excluded. So what are we going to do about it? This is a learning moment for all of us. How *do* we interact with each other in a community where many people are dealing with serious health, emotional, financial and relationship issues that come with this disease? From our perspective the answer is not that the admins enforce rules, but that we each take responsibility for our words and how they will affect others--by becoming more aware of each other, by cutting each other slack, and by apologizing when we have hurt others--by being and acting as mature adults. We believe that everyone who comes here should act as an adult and a responsible member of the larger community. Sharing information and experience, or voicing agreement or disagreement are all good, it helps us learn. Rudeness and insults don't work, they don't help anyone, and only take away from the group and diminishes the discussion. Should we chastise those who are rude? Sometimes I want to, but doing so would change the dynamic of the group in a way that we do not want. We want you all to work things out whenever possible. There are some behaviours we will not accept. There have been cases where people have 'attacked' others by name, and we have addressed this with them in private. There have been cases where people were clearly here for the wrong reasons (looking for dates or for someone to buy their products), and we have revoked their memberships. But people are going to offend others, and if it is not a personal attack our view is that the community needs to work this out. Yes, it can be difficult, especially where we cannot sit and talk to each other face to face, but we do not intend to be the "forum police" where we enforce etiquette and good behaviour rules. Like most of you, we cringe when we read some posts, but at the end of the day we're operating on the philosophy that you all should and (usually) will work things out. If someone is clearly out of line we will step in, but that is something we prefer not to do - by design. Our Code of Conduct describe the ideal member, and we accept that there will be times that every one of us behaves in a less than ideal way. Some of this behaviour seems to be the stuff we need to cut each other slack for. People have opinions, bad days, pet peeves and aren't always diplomatic in how they express themselves. That's life, and we need to each deal with it in our own ways. Some of it is not appropriate and needs to stop. And sometimes we need to take the advice of an earlier post: "If you can't come to an agreement, and like us, you're not interested in the nastiness, then skip the offending threads and get back to stuff that keeps our nearly 3000 members coming back here: sharing useful information, not drama." This as a learning moment for us all. As site admins it leads us to question if our approach of group self-management works, or are we being too niave, too trusting? We'll keep working on this, trying to find the right balance that works. We appreciate your support and encouragement in this journey. (Tim, admin)

There are some who simply like to set of a bomb and watch the mayhem. They get some kind of weird sick thrill from it. If it wasn't for this code of conduct, this sight could be flooded with people like that, and it would no longer be a safe haven for those that are looking for information and help. If we get people like ru in the future, we should probably just ignore her instead of feeding the flames, or trolls, or whatever. This is just a suggestion:-) Don't want to be called a Nazi. (screamer, mood community)

I think it's also important to remember that we don't have benefits of face-to-face communication, like inflection of voice, body language, eye contact, etc. It's easy to attribute certain emotions based on the words you read, but those emotions -- or the perceived strength of the emotion -- often don't match what the author intended. You can only do so much with punctuation and smiley faces (jeremy, admin)

(on a member wanting a thread to be closed): 'Regarding the request to close threads, I recommend you read our blog post about "Light Touch Moderation". It gives some good insight into our philosophy behind letting members work out their own disputes. I can't speak to what's been done in the past, but it's generally our policy not to close threads except in the most extreme circumstances or in the case of duplicate/mistaken threads' (Moakes, admin).

the best thing to do with a negative thread is ignore it- don't let it bring you down or affect your enjoyment of other threads. Threads that are contentious will burn out eventually, and all the quicker if there is less attention given. Sometimes people seem to get drawn into the drama and we see a cycle of explosive comments, lots of attention and division, some people may choose to leave, others object, someone apologies and things start to settle down again. I understand why you think that closing the threads might work but it often seems to move into another thread and start up again. Better to let it burn itself out. Of course a different story if there is an issue that contravenes our user agreement. Hang in there, it will come right Best wishes, (LisaE.)

I am one of the paranoid internet types, I have had privacy filters so not to have anything from the internet impact me, I have 2 firewalls, I don't go anywhere that is not trustworthy. Now after saying that I feel trust with PLM with information I don't even share with personal friends and some family. This site to date has been stellar with its morals and ethics with information and how it is treated. so Thank you from me to staff of PLM for that (NickAtNite)

The proof is in the pudding. Ethically........This place is heaven. Truth from real patient w/out humiliation. Stay the course.......don't sell out to advertising (like a webMD) and make other patients' dreams (i.e. like taking their family to Hawaii) a reality…My health has honestly improved as a result of this site's work! Thank You. All you guys "Rock"...... Todd (Smallie)

(On closing forum threads that involve personal attacks when members talk about politics or religion)If admin starts closing threads that people are having a problem with then the site should strictly go back to MS. I definitely wouldn't be here if that happened. I would take my little information and leave, like some of the "older" folks have already done. Remember, when you start censoring for the new people and closing stuff down your losing many of the old members also. We have to find a happy medium here. The rules clearly state NO PERSONAL ATTACKS......how hard is that? In whatever subject we have. This site is becoming just like the world has become, it doesn't matter how many are in favor of, let's say religion, but if 2 people don't like it and bitch about it, it gets taken out for everyone. Thats partly whats wrong with this country now.........the majority does not rule anymore. (KaKiJade)

I don't think that Tim meant that we have to have censorship on here. I think that he meant that the whole tone of the forum was getting way too negative, due mostly to those few who can't control themselves, and that it was keeping people from coming here, and that some people were leaving because of it. Tim is just trying to make it be a place of refuge again. A place to find a calm spot in the midst of all the ms chaos that we all face. I, for one applaud his effort and hope that it works. Jan (GramaJan)

The code of conduct is set up for a reason, so I think if people are getting out of line they need to be warned and then if they are not listening removed. Its not an easy situation that Tim and the Admin are in, i do not envy them at all. I am just trying to look at both sides here, and there are two sides. I don't like when people are attacking people I love and care about. I don't like that people are leaving, but I just think this is not an easy fix by any means. Be Blessed Cindi (thiagirl)

administration/PLM has provided us with a wonderful forum to discuss our MS, relative things, allows us to post personal thoughts and most anyting else we desire. they have other things to do than to continually step in the middle of disagreements....on any thread. no, it is not solely political threads which have caused disagreements yet, these threads/discussions bring about the larger number of disagreements. it is their site, there are rules and the sincere desire from PLM to provide a platform for us in which to discuss many things and most anything. it is not as though this is something new when it is asked to not discuss.... POLITICS AND RELIGION. this has been around forever in the work place, in business, personal situations and many other facets of life with full knowledge of what discussing POLITICS AND RELIGION can cause create and destroy..... tim couldn't have asked more politely, over and over again for some compliance in this area to keep the peace. they do not have to provide this forum for us which undoubtedly provides us with far too much to mention.(NewLife)

I don't like PlainTalk's enrollment policy. This may've changed, I haven't been there in months, so please correct me if I am wrong. I see no reason to limit new members to the 'meet and greet' forum until the committee (whoever they are) decides the newcomer is welcome into the meat of the community to read posts about symptoms, treatments and such. After all, if someone disrupts the forum, they are only a click away from being banished. Also, there doesn't seem to be a certain number of posts before a newcomer is accepted into the community. It's arbitrary as far as I could see. I feel that this is a hurtful policy. I also can't support the idea that if a member doesn't post for 30 days or so they are deleted from the forum. People with MS get sick, sometimes for months, and the last thing on their mind (might be) is notifying MS forums that they'll be away for a while. I like the idea of a protected community (from Goggle) but not that protected. I was accepted into PT without any post into the welcome forum. This is not a post about bitterness (should that thought arise). I love people and I don't like to see anyone hurt by forum policies. Inevitably that will happen but let's try to be trusting and loving and open our hearts to everyone with MS. I hope we don't adopt a similar policy here. Everyone with MS should be welcome (Joy)

Hi Joy, Thanks for letting me know about that, I wasn't aware there was a site with such a policy in MS! I imagine there are a couple of factors influencing that; many people with MS may want to keep their condition private, forums can easily be thrown off balance by trolls or people selling something, and bad experiences in the past can make established users wary about newcomers. We will have a policy of monitoring what goes on in the forums and on people's comments pages, but with a view to protecting the community from unwanted influences rather than individual censorship or trying to intervene in disagreements. We do have a community code of conduct (when you first click on "forum") which we hope people will follow and so far it's worked very well! (Paul Wicks-support)

I am a member of BrainTalk and love it. I, myself, have never recognized a "clique" though, but then again, I never pay attention to those things. I like that it is "public". I tried a "private" forum once, and did not like it at all! You had to earn your way in by proving you are not a lurker, and people had to approve you?? Kind of silly IMHO. And, like stated by someone here, they are more of the WOOHOO and "chit-chatty" type and I am more of the info type. I have been to MSWorld, and remember liking them. Again, more informational. I completely agree about having a separate BACKUP!! Great point! Oh, more icons maybe? I think you have a great thing going and wish you the best in making it a success! (jca)

c) Strategies to deal with controversy in forums:

c4) PLM: practice for real life, and practice a different life

I agree with Millie, I love the discussions. It helps my mind stay active with the yen and yang of people's views…Honestly, and I don’t mean this in a bad way, I enjoy the flow of people coming in and out of here. Cheryl (oknowwhat)

We come in all shapes, sizes, colors, and backgrounds. This is my classroom for life. I have learned from each person who has opened up on this site. If I have grown as a person (and i am pretty sure that I have), its only because of the people i have met here. Shyanne, mood community

you expect plm to be more supportive and it's not. there's nothing wrong with that, but just keep in mind that you are also a part of the equation. obviously if you're not posting then you won't get a response and if you're not expressing yourself in a post then people most likely won't relate to you. having said that i appreciate that you at least came here and were honest about how you felt. maybe now that you see you're not alone you'll hopefully be more inclined to use the site. i just encourage you to take things with a grain of salt. i mean, this is a forum of people with mood disorders.....you can't really guarantee what you're gonna get. if someone reacts to you out of sadness or anger or mania it's not gonna feel good, but it doesn’t have ANYTHING to do with you. you are 100% legit in how you feel and wanting support out of this website. but how you react to what you get is in your hands. it sounds like you're on the right path by just posting this thread and i believe the anger will subside....just don't give up quite yet. i feel there are a lot of resources and genuine people here who can support you. i'll be praying for your anger.......i think someone already recommended it but meditation has really helped me a lot with my expectations and how i react to things. maybe you could consider it? no pressure of course. try and have a good day man. i am really good at listening to people rant if you'd like to give me a try sometime:) i'm wide open in that department........ (auntda06, mood)

To me, PLM is not only a place to get support, but to grow which sometimes hearing things you don't particularly like. I think you are a case in point. Alot of us were befuddled about how to respond at the start of your thread but alot of us have grown from it. Gary715, mood community

Why and how of ‘NOT SHARING’ private health information in PLM:

1- Cliquing away Inclusion:

Old Dawg, You have been a member here for almost half a year, a long time in the life of this unique group. You have posted 1150 times, and other members gave you 848 helpful marks - both some of the highest numbers within the members of this community. As we grow there will be people with whom we do not agree, and there will be people who try and shape the community to their view of what a community like this should be. That is a natural part of the dynamic of a group of people who are growing and learning together. This is a part of our growing pains. Our hope is that those who have helped us grow to where we are will be a part of the process of working through those pains. Some will take this on, some will walk away. No matter what your decision, or anyone's decision, we at PatientsLikeMe will honor it. If you decide to walk away, we will miss you, we will wish you had stayed and helped shape this community so that it worked for its' members, but we will respect that you have to do what you have to do. But know that the "door" here is always open. If at some later time you decide to rejoin us, we will be delighted, and we will gladly reinstate your membership. While this is your decision I will note that as a member of a dynamic community you could also join us as we face the challenge of how to help shape and grow that community so that it "works". Leaving because you perceive that it is irrevocably changing may not be fair to all of those who have also contributed hundreds of posts and much time helping others here. My advice is simply that if you don't like what's happening, work to change it. If that fails then it may be time to leave. I'm not sure your work here was done, and I sense your leaving may be too soon. But, again, that is your decision, and we will respect your decision. (Tim, admin)

you have been such a huge support to so many people and have shown that you truly care and offer sincere and compassionate advice and prayers. I kind of understand what you mean though..the dynamic of this site has changed a bit and that is why I have taken kind of a back seat lately as well. But, please don't go..can't you just take a break and see what happens? Never hearing from you again would be not good for so many people that truly value your input. Whatever you decide, I wish the very best for you. Jen (jenj)

I have been a member here for a long time. I have never heard or read or a hint of a clique in here. So I have a QUESTION: No disrespect to Kelly he is my friend as well as all of you. How do you know it just wasn't Kelly himself. With all the meds that we all take maybe it might be a side effect of a drug he is taking depression can do some strange things. I am not saying that it didn't happen but this is another side of it that we need to think about. It might be very real to him. PLM is a fantastic place for all of us. And I am so thankful to the staff for having a place for all of us to seek refuge and hope and friendship and even more answers. Thank you for listening, Laya

i'm a newbie here too - sometimes just sitting back on the fence - read and learn - i'm in awe that there is anyone here that would come across as defensive, demeaning or otherwise.. some of the posts do get off topic - some might be what is considered crass..but just don't read them - move on to the next - get on with it..and get over it.. we're suppose to be adults here.. i didn't know kelly but never found any of his posts out of line..and i see from the above posts that he has many friends so he should stick around and to 'ell with the rest. remember computers can be your worst nightmare as it is easier to attack or make comments from behind a screen where no one sees you and you really have no accountability but a name on a screen.. i find it disheartening as a new member that someone would be driven to leaving.. (gcat)

Dear Friends, Please end this thread. It is not healthy. It's exactly the same dynamic as that of a small town where a crime has been committed. We suddenly begin to see other differently. Everyone is a suspect. We are all uncomfortable. We speculate. We even question ourselves. Kelly must have been very angry to have announced his departure in such a public way. He could have sent private messages to those of us he wanted to keep in touch with. I did want to discuss this with him when he said goodbye but I didn't want to pry (though I was dying to know...hey I'm human...) I might tell him about what he left behind, because as angry as he might have been, I doubt he would have wanted to create chaos. Because this is the definition of chaos. Some powerfully negative words have been spoken here. There was talk of new people trying to change things, that things were better at the beginning when there were fewer people (I've only been here three months so I was hurt by that), "YOU SHOULD BE ASHAMED" was shouted out several times though no one knows to whom it was being shouted, someone mentioned persecution for religious beliefs, and a seemingly non-existent clique was invented out of whole cloth. These words are unproductive at best, perhaps destructive. And those sad goodbyes, though understandable and heartfelt, will never be read by the person to whom they were intended. I do agree with the person who suggested that if the administrators are aware of some wrongdoing, or the existence of a clique, we deserve to know. Anything is better than aimless speculation. I'm going to shake this off and return to the PLM family I believe in. The collective spirituality, the healing magic, the love. Diane (WriterLass)

2- Dealing with trolls or ‘poseurs’: Pay no attention, police, and present

When faced with a debilitating illness such as MS, many people grab at any straw that is shoved at them. We all want a cure. Right now there is none... just some DMDs and meds to help with our flares and symptoms. I hate taking the handful of pills I do 2 times every day with some in between. I hate taking shots every damn day. But if that's what it takes for me to function (not even normally, just function) then that's what I'll do. If you are referring to the person I think you are, I can understand where he's coming from. I have expressed my concern about some of the "alternative" therapies he's wanting to try, but it's HIS life. I don't feel that he's trying to "sell" anything, but rather expressing his views on a medication that's helped him. Tim and the other admins are usually right on top of improper posts, and if they miss one, someone usually PMs them to check them out. IMO, if a post bothers you, report it to the admins. Then ignore it. Best Wishes. Nana (NanaBanana54)

3- Unfit Connection:

3a) Undiagnosed, Newly Diagnosed, and Less progressive stage patients:

Undiagnosed or less progressive health stage patients feel disconnected: Bossofmyms - no no no no!!!! Please, this is a site to help people dealing with MS, whether officially diagnosed or not. You'll see that a good number of people here have not been diagnosed, and some waited for some time before it was "official". You are using the site to learn, and we want you to do just that!!! (Tim, admin)

We all come to this site for the same reasons. To vent, be understood and to understand others. As for the "cliques" I'll be the first to admit, YES we have a clique, but its a BIG one, its called PLM. And if you stick around long enough you'll be in it too. Cliques happen when you get to know people, get comfortable with those people and you become friends. There’s nothing wrong with that. I've never shunned anyone because they were new or undiagnosed. The longer your here, the more things you'll see, and the more things you'll learn. We have thousands from around the world. Shoot I think we've added more new people in our so called "clique” lately. So if you wanna make friends and talk to people, stick around. If you don't want to, that’s fine too (Kakijade, Mood)

More members are here and more are posting. Like kykass I go in spurts. We have/had and continue to have to off-topic discussion quite a bit. Most likely we will continue to do so, this is a good thing as it helps in keeping the community on track. We also can't control who, why and how people respond. IMO that's the essential basis of a forum and PLM is no where close to a chatroom...from what I remember of them. Everyone needs to remember that a lot of us have concentration issues. Also, who determines what is on-topic and what is off-topic? If I ask a question and people post additional questions that may have surfaced as a result then technically they are off-topic but, since the questions are relevant to the main post then they are on-topic (JavaJunky, mood).

I think everyone can benefit from PLM, regardless of your MS stage. We all can learn from one another, regardless of our stage. We all have an incurable disease that changes who we are, and how we live. We are the same in many aspects, including that one. Many are scared of the unknown, worry if we will wake up the same person, etc... I know I do. I worry everyday mostly about how my decline in health changes who my children are as people. That is the biggie for me! PLM changes as new people arrive, people grow and learn. New and different people all the time, with new and different problems AND support. I personally try to embrace these changes, as well as the people (jca, MS).

Kelly, MAry, Heyden, all you other fellow PPMSers AND the other categories of MS, What a thoughtful posting from Kelly. I feel much the same as he does, but whenever I take the time to check in to the forum, I still find places to weigh in with my thoughts, etc. I do agree that others may not find much validity in our experiences, BUT if and when they turn into SPMSers or God forbid, PPMSers,I think our thoughts and experiences should still be out there (garlicfrau, MS).

When I refer to the other side I mean the MS part of PLM. It whizzes over there. We have what close to 2,000 posts when they have over 10,000 posts. They have twice the members as well. The forum setup over there is exactly the same. Everything else is different to accomodate for MS related symptoms. I've been around for a while and watched as PLM evolve into what it is now in the mood community. When it all started changing I bitched but then I joined the MS side and now I can't bitch. Seeing that makes you realize that it's not so bad over here. It reminds me of when they were changing the way we did things at work and everyone complained and they were nervous that they wouldn't be able to hit their quotas. It eventually turned out that change was for the better. The system was smooth and it was even easier to hit their quota. Remember that you can't just build a website overnight and it takes time to make it work really well for the users and the researchers. There are a lot of people on there without an M.S. diagnosis because M.S. can take years to diagnose depending on the person. A lot of them say they have M.S. Just so they can track their symptoms. So I couldn't tell you how many people without M.S. post on the forums. I can tell you this though if you post a topic and no one responds it can disappear 3 pages back in half an hour. They do other things like little games to keep theirinds going because that's one of the first things to go. They also post pics about their family's and information about MS walks and conventions and those types of things. They also try and help as much as they can. There are far more people over there than here that are undiagnosed. I kinda felt guilty not having a diagnosis, but a lot of people asked me to fill out my profile and said it would be helpful to track my symptoms and to help them understand what I'm going through. (Ender, mood community and MS community).

ok since i am on the MS side also my answer to your questions: 1. i would estimate that over half do not have a dx they even have a post for all those who do not have a DX, 2. they are extremetly active on the forum trying to learn all they can so w hen they go see their dr they are armed with information and not be caught unaware. knowledge is power with any disease the more u know the better u are. some have not been dx for yrs and yrs and are still waiting for a answer but we welcome all wheter dx or not and yes it can get frustrating with so many repeat questions we are up around 7,000 people and growing daily. ender is right the posts can be on page 3 or 4 in just a few hrs over there. as with all the communities there are people who just do not fill out their profiles which is a shame because when they ask for help we have no clue how to help them if they do not give us any info about themselves. data collection is what helps us get our drug companies to stand up and pay attention to what works or does not work for MS. yes even over there some get lost in the crazy posts like bassongirl over here.. we all hurt as each community in their own world hurts. but if u shut off the site to only those who are dx than that would be a shame because there are those out there that want to ask questions to learn to be fully armed when they go to see their drs.. yes each community is unique to its own board. i have been on mood side before it was open to the public so i have watched it grow by leaps and bound with good days and the bad days.. one thing i do know is that we all hurt, we all want support and a safe place to come to to vent, to ask questions and get support no matter what disease we have dx or not. edit to something that ender brought up before yes most of us sign our real names at the end of our posts and yes alot of us has met in person and we post pics of our vacations to our pets to our kids. lifeb4ms (MS and mood community)

3b) Oldie-Newbie Distinction

I've often found it profitable to go by the old adage" the only stupid question is the one unasked". The ocean's of mental illness are quite deep and unchartered and I give more credence to the observations and experiences of those who are immersed in it than those who pontifically preach and prey upon it from the shoreline. I checked out a few similar sites prior to discovering this one and somewhat favor the flavor of this one. D'ont let the sharks keep you out of the pool; they're fairly friendly once you get to know them and have their own portion of wisdom to share… (barbou2, mood)

Everyone has something to add, no matter how long they've been diagnosed, what type of symptoms they have or don't have, what type of MS they are living with, or how long they've been here. It is the incredible diversity, I think, that makes this place such a wonderful gem. Stick around and share your unique perspective! I am rather new too. And I have found this place such a blessing. Some have been more than gracious and kind in their welcomes, some others not so much. I understand that it is hard to share you sandbox with the new kids in town - especially when they come in by the hordes, which seems to have happened here. I just want to say thank you to those of you who came before for sharing this space with all of us. I'm sorry if our being here has made an uncomfortable change for many of you. That has got to suck! But in the same breath, I want to say, so many of you have been kind and welcoming and comforting and gracious, in spite of the 'newcomer invasion.' Hopefully, change won't make many of those who were here longer stay away too long. You all are wonderful. We all have so much to add to the tapestry. Each thread (person) has something to add to the beauty of the picture here. Thanks again for each of you who share all of your experience, expertise, opinions and even funny, off-the-wall stories. You have been a huge blessing to me. Thanks to all of you who have been so kind and welcoming. As Kendra said, we all have one huge opportunity and responsibility to reach out to others like us who may benefit hugely by what kindness and knowledge we have to give to them - let alone how much we all get from this wonderful site!... It is indeed like breathing fresh air to come on here with fellow travelers along this road full of the unexpected. Liz (lizupatree)

Support sites are very cyclical, members move on, new ones join, the family grows, just as it does in our own families. I've gotten the feeling at times that some members are unhappy about this site growing. I understand, it's hard when new people and new personalities show up. But I have learned from all of you, and I have things to share also. Until very recently I was afraid to reach out and share, I didn't feel welcome, and I had been here for weeks. That's not a dig at any of you, truly, it's just the way I felt, and it felt very lonely. Another site I'm part of is very large, it wasn't always, but it is now. People come, and people go...I am always happy when they come back. I think the more voices in a place, the more stories and experiences to learn from. The more people, the more personalities to make the place like a REAL family. Jen (Feisty)

To all of the new (ish) people: Please don't feel slighted if old (er) members seem to all know each other, and to respond slower to the posts of newbies. It's not meant as an insult, and no one is trying to ignore you. With so many people on the site, a post can be pushed off the front page rather quickly. If you need an answer, bump your post by replying to yourself. Hang in there. More people = more voices = more opinions. More people means more diversity on the site, and I think that's a good thing (gardener, MS)

i have found i can learn something from anyone on this site....it doesn't matter the new folks, the old folks and the one's somewhere in between. i like to think i can help the newbies, the old folks and those somewhere in between. i can help the newer people while they are desperately trying to make adjustments and learn what this disease can and is doing to them.....i can help the older wiser ones, maybe by making them laugh on a day they feel blue or just finding a new friend....i get to learn so much from them as well.... and the one's in between are very special as they remember very well what they have just overcome and are still figuring out as they move into one of the "old hats" with MS.....which i guess is where i fit in:) surprising to me, i have also found i shared information with very seasoned MS'ers which had never seen the information i shared. there is so much knowledge, there are good resources everywhere.....we all look up different things and have so much to share. (NewLife, MS)

I read through the past threads and see that it's frustrating for some older members when newbies post threads that have already been discussed, thus making their threads disappear faster. That makes me feel guilty, lol, I feel like I've intruded on a private club that wants no new members. I can totally understand how it would be frustrating for a small, helpful community to become inundated with new members who don't stay for long, or who don't understand the way things are done here, so to speak. I just stumbled upon this site when I googled depression, as I've done countless times before - trying to find help. It's def. been a great help to me - finding people who are understanding and deal with the same problems. (appleflower)

Something I dislike that I can't be helped: The regulars here have formed bonds of friendship and shared experience. They have learned something of each other's background and build on that in their conversations. It is a true community. New members often feel like this is a "clique" that is hard to break into, and feel put off by it. I know it hampered my participation when I first joined. Maybe there needs to be a section of the "New Patients" page that explains that:1) There is an ongoing community here, which is one of the reasons for the forum. But it is not a clique. 2) The community is very welcoming of new members, who should feel free to post on any topic, whether it's new or a continuing thread. 3) It really helps when new members take the time to fill out their profile, which more experienced members use to learn more about members. There was a recent thread about this, but I'm not sure if it was entirely successful in convincing the new member of the openness of the community. Like I said, this is something that can't be helped. It's human nature to feel like an outsider when you step into an ongoing community as a new member. But we can be as welcoming and encouraging as possible to new members, and help them to feel free to participate as any member of the community. (mnichols, mood community)

Sial and others who have offered their thoughts about how things at PLM are changing and that it seems like some of us old timers are not posting as much... i appreciate and agree with most of what you expressed and why. My view is that basically we all want to have a sense of some continuous community because the "actual" world around us can be so impersonal and disconnecting, so we come to view our virtual community as possibly a more predictable and safe place where we look forward to "seeing" our old friends. Part of this is also exasperated by how sensitive to change we can be and just things in general (Chelena, mood).

Chelena, we will always be more focused on the data-gathering and basic functions of the site, because that's where our expertise is. We build the tools, we set a basic level of expectation of acceptable use of the site (the user agreement), and a code of conduct we hope people will aspire to in the forum. Almost everything else is determined by the community members. Each community here on PLM has a different feel, determined by the number and age of members, the different types of illnesses, their familiarity with using online tools and communities and other factors. As we gain more members, some things are bound to evolve and I hope some of the "veterans" will stick around to help the newbies learn from each other continue the great community that you all have built here. That said, we are aware that the forum needs more structure, and we're working on some tools that will help. Hope you'll all stick it out until we get there (Moakes, admin).

Oldie Responsibilization to increase Newbie participation:

we'd love to hear your ideas - what can we do to keep people coming back? (Tim, admin)

I was just thinking that emailing them something short such as, "Thinking of you , hoping that you are doing well"......."would love for you to drop us a line if time permits and let us know how you are", or "You've been missed, wondering how you are'??? I am sure that you can come up with the wording. Something short and simple. (Jenn 5420)

If it comes to delegating people to drop them a note now and then, I have time and would be willing to help in any way possible. I'd also like to point out and recognize all the wonderful members who go out of their way to say "welcome" to anyone they see has less than 10 posts under their belt before responding to their question. I know that for many joining a place like this with nearly 10,000 members can be overwhelming and daunting. So if five people answer their post, and all five have noticed they are fairly new posters and have gone out of their way to welcome them, I know it makes them feel comfortable posting and sharing. Liz (lizupatree)

My heartfelt thanks to the founders, administrators, especially Tim and Mureen, the teckies who kept the site going and enhance it. Well done! I also wish to thank the welcome team. I wish to thank all our caregivers. Caregivers are very special people. Without them, in many cases, out lives would be empty. In al cases, they add a special dimension to our lives. Last but not least, I wish to thank everyone of the members. You are truly incredible. I have come to learn it is impossible to gauge the impact one person can have on another. Allow me to say, all of you with our caretakers are the essence of PLM and the support and compassion I have received is greatly appreciated and boundless. Susanna (heyden)

4- Patient and Administrator Censorship in Forums

4b) Administrator censorship of controversial thread topics:

PLM has better things to do than to oversee a thread 24/7 to see who can/is behaving and who is not. seems like everyone would have better things to do... why should PLM be responsible to make "time outs" for anyone who is not behaving properly? warnings, suspensions???? i doubt this is what PLM intended when they began this endeavor. the box is bigger than it looks from the inside….what i do care about is PLM. And when the administrators are being asked to watch over threads which continually cause issues by one, two, three or however many ppl.... then it affects me as well. because i am part of PLM and i feel offended that they are asked to supervise a thread which causes so many issues (NewLife)

IMO, PLM is for ME too, and for many others here that rely on PLM for most of our social needs. Can it not also be called selfish to ask that we not talk about things (that many clearly have a passionate interest in just as some do for Prayers and Religion) and threaten admin so they will close the threads when those not interested clearly have the option to not go into them?? If you do not go in, how can it affect you? Also, there is NOT ONE MS site out there that is not monitored by moderators. They ALL are. (jca)

Who's fighting? I thought we were discussing.....since no admin has responded, I guess they have left us to work it out ourselves, which is fine too. For those that keep coming in here and posting that its so offensive to you, don't come in here!!!!!!! Simple as that. There are many other topics, MS related or not, and there IS a search box located at the top of the forum for you to find answers to questions. Feel free to search anything your heart desires. No ones arm is twisted to come in here and read.........step away from the mouse and do not click! (KaKiJade)

We are working on solving this problem, but it's not going to happen as quickly as we'd all like. In time though we will have tools that will allow members to identify the types of posts they are interested in (or not interested in). A week or so ago I posted about work we are doing on tagging and other forum upgrades (see "PLM: Coming changes to the site (tagging and reminders)" for more details). The tech team is working on the first piece of this now. There is more work there than some may realize (tagging interfaces, reference tables, admin interfaces, UI designs, forum design changes, etc.) so it takes time. In its' initial implementation we will have simple tags, with the plan to understand how these are used by each of our communities before we "bolt down" categories. Keep in mind that we have 8 forums across our communities, each with somewhat different information interests, so we need to do this in a way that will work across the larger site. We really (I mean *really*) don't like being put in the position of asking people to to not talk about heated topics. It was not an easy decision, nor one we took lightly. It was disheartening that some could not respect our request, and took it as a personal insult. It wasn't, really. It was the only way we saw to get the forum focused and away from the tensions that had been created. Hopefully in time we'll have tools that will make it so we never have to ask that again. BTW, we realize that prayer and community support are critical parts of how people deal with issues, and we have not considered 'banning' such posts...(Tim, admin)

Tim, thank you so much for the great efforts being made by you and all the tech guys who are working toward a better PLM. I know it takes a lot of work and cannot be accomplished by just the snap of the fingers. We sometimes forget that you are actually human and not the mythical magician we see you as. It is so sad that it has come to this. I am just hoping that maybe in time some who left angry, bitter, hurt or offended will return. I am hoping that since they didn't actually cancel their profiles, they still have their foot in the door and will return when tempers have cooled. Liz (lizupatree)

The truth be told there are no winners here. there were two sides, and somewhere in the middle the truth. I think each side had valid feelings so then that means that not everybody was wrong and not everybody was right, and in the end we all lost . That is the part that is so painful. if you are sitting here today feeling like something was gained here, you are quite mistaken . For the members who left because the politics were being discussed and to the members who left because they couldn't be discussed, but we are all losers here today. It hurts to see that. Nothing was won here. it is a lesson that in wars there may seem like there is a side that wins, but the fall out in the end makes both sides losers. Be Blessed and lets try to get back to being here for each other Cindi (thiagirl)

we entered into a mutually beneficial agreement with PLM when we joined this site. We benefit them and their operating costs through our posting of personal medical data that is shared/paid for by researchers, companies, etc..They benefit us through the use of this forum and the community-building that comes along with it. So, as far as I can tell, when some found that the MUTUAL benefits are no longer, i.e. the forum posts had become censored because of the hollering of some and the threatening to leave/actual leaving of others, then they pulled their data. I can understand why this is happening. Steph (sacleveland)

The forums were causing problems. Most of the posts at the top of the page were about politics. Several people were insulted by posts made, some marked as OT, some not, and left the site, disgusted that we allowed this to occur. Right now we do not have the tools to put posts in tabs/categories, nor can we move them once created, nor can we spend 24/7 monitoring what gets posted, and how it gets marked. Given the problems these posts were creating, and our own shortcomings (which we're working on) asking people to stop the posts that were causing problems seemed reasonable. Not the best solution - being able to have them in their own space would be best - but a way for us to do what we're to do. Given there are any number of other sites where this topic can be discussed this seemed reasonable. We couldn't provide the solution people wanted, so a few have decided to remove their information as a message to us and find a new home. Because we asked them to stop doing something which we viewed as disruptive. Disappointing. Tim (admin)

I would consider myself an expert of internet based forum websites. I am a moderator of a community with about 5,000 people. I have been an operator for a very large IRC network (yes, I am a nerd) for years. These things normally don't end pretty, on both sides. If you allow politics, a group of people will leave. If you disallow politics, a group of people will leave. The question becomes, which impacts more. PLM is interesting since we get a service in order to provide our information to sell. If you take away the service, you lose money. If you don't take away the service, you lose money. I don't know what the solution is for PLM however I have found that the more you censor the more the drama. I know LiveJournal has had these kind of problems and most of the time, they have had to pull back and remove their new censorship because of the backlash (ninaf)

I've always enjoyed boards for their community atmosphere of the subject I'm interested in and the fringe benefits of the personalities I get to become friends with. There were other boards I checked out before landing here. I actually found PLM by hunting for the place the Flutterbuds had been after reading their books about living with MS... and realized I'd found the board I could call home now. But as Liz pointed out, sometimes things get ugly and usually when that happens, I'll just lurk and stay quiet... ugly posters don't deserve the finger time and keys. Perhaps that would be the best way for any community to deal with them. I learned a long time ago from an old college professor about a Chinese saying, something to the effect of: We give all thought meaning. Translated, we have to make it important to ourselves to make it mean something. So when someone gets ugly about anything, I just don't make them important to me, and pray hard the folks they're attacking don't either. Like JCPenney, they've got a lot of clothes but they don't all fit me, so just because someone thinks something of me, doesn't mean it fits me. Therefore, I can walk away, be ok, let them be unhappy in their own ugliness. Thanks for sharing Patty, really, the forthright honesty was great and transparency is always fabulous! What a wonderful world it is when we can see clearly isn't? (even in our brain fog! ((D'awesome)

All democracies and even all communes have some form of law enforcement, Tempest. Moderation of the board is reasonable to expect from Moakes, especially when people are fairly warned. I'm not happy beck is gone; I'm also not happy with what she did. But that was Her decision to act in a way that Made Moakes have to delete her account. She's a big girl; she must be held responsible for her actions, just like everyone else here. Please don't blame the moderator. (patient, mood community)

The PLM Mood Community needs more of a moderation presence. What's more, the community wants it. We're depressed, anxious, manic, angry, and depending on the day, more than a little crazy sometimes. That's why we're here. So we need guidance when people start to decompensate. The issue, as I understand it, is that PLM does not have enough manpower to properly patrol the forums. That may not be too much of an issue in the ALS community, but it certainly is here! (See above. We're a pack of crazies when we're the instant mood icons start turning black.) To compensate for this, we need volunteer moderators. These mods wouldn't need to have all of the powers that, say, moakes has... but they could have some extra bells and whistles that would help keep the forums a safer place for all of us. What would volunteer mods be able to do? * They would have a (mod) designation under their names, much like moakes has the (admin) designation. This would help with recognition when fires need to be put out. * Because of this, mods would be held to a rather higher standard, never making the personal attacks they are meant to patrol and prevent. Any violation of this would result in removal of mod powers. * Mods would step in and give the "first warning" when a thread starts to get out of hand. They should be able to see when another user reports a post in a thread. * If the first warning isn't heeded, mods could hand out temporary suspensions. The suspensions would either be time limited or could be lifted once moakes can review the situation. And that's pretty much it. Volunteer mods could never replace official forum admins. (twilightsun)

I'm going to try to re-word my original post about this because it doesn't seem like my main point has been understood. I am reading that you all think "the wrong one" was banned, but as I said before- b3ck's removal was not about behavior over those few weeks of nastiness. If that were the case, there would be justification for lots of accounts being closed, including many people in this thread. The point was that I sent messages to several people saying we were wiping the slate clean and starting over from that point. b3ck was the only one who posted nastiness after I asked everyone to cut it out. She replied to my PM saying she knew that she had left me no choice but to ban her, and she did it anyway. She felt it was the right thing to do. I fully agree that people should get second chances. That was b3ck's second chance. Those of you who think this is inconsistent with the Ender situation should know that although he took several breaks on this own, I never banned him because every time I asked him to cool down, he did. As I've said before lots of things happen behind the scenes here, and sometimes that gives you an incomplete picture of how events unfold. You can always ask for clarification- I'm happy to provide as much as I can- but not everything is a decision for the forum community to make. The PatientsLikeMe community is much larger than the forum users. I also want to emphasize something QuietGuy said a few pages back, "I cannot believe the solution is to pressure moakes into shortening the suspension, which sends a message loud and clear that the rules are inconsistently applied and subject to the whims of administration or the popularity of members." The existence of this thread makes it virtually impossible to change my mind about b3ck (not that I was going to anyway) because it would send a message that with enough badgering and drama any decision can be overturned. I hope we won't end up in this situation again, but on the off chance we do, it's worth pointing out that this thread is not helping b3ck's cause. It has however, helped elucidate some useful site suggestions. We can't implement them all, but I'm happy to listen to each of them. In this case we have talked about adding the ability to deny members access to the forum without closing their accounts. I think it's a very good idea and if and when that change becomes a reality, I'll be sure to let you know about it (Moakes, admin).

From State Intervention to Community Intervention & from Privacy to Sharing:

An impressive list of health geeks and supporters of patient empowerment have launched **HealthDataRights.org**, a new blog that seeks to ensure that patients regain control of their data. Most people don't realize it, until they try to get a copy of their medical records, but patients have no inherent right to the information that providers keep about them. The growing "patient-centered care" or "participatory medicine" movement is hoping to change that. You'd not only get easier access to your own medical record, but you'd able to check the sources of the information in it and use it to find your own answers to your medical problems. The idea that patients are wrenching their records back from the hospital and doctors' office vaults where they are so well protected has some people wringing their hands. I'm sure you know that as soon as we have access to our health records, they will no longer be secure," one M.D. has already commented on the HealthDataRights.org blog home page (Source: PLM community blog that links to www.healthdatarights.org).

Security is obviously a huge issue, but most experts feel that the majority of our medical data is already extremely vulnerable. Remember the **Express Scripts Data Breach** that occurred last November? And, as I just **wrote**, poor Farrah Fawcett had to endure the indignity of having her medical record regularly perused by a UCLA Medical Center staffer who then sold choice bits of information to the *National Enquirer* (Source: PLM community blog that links to www.healthdatarights.org).

I think that for most people who are ill, getting ready access to their own medical record is actually much more important than protecting their privacy. You can't shop around for a new doctor, do your own research, or get a second opinion without your record. Patients and caregivers spend inordinate amounts of time waiting for copies of records and then shuffling them around. And how often do you get to that appointment and they say "Sorry, we didn't get the record yet." Even worse, what if there's misinformation in your file? It happens, and the consequences can be dire. The whole medical record process, as it stands now, really seems Medieval. (Posted by PLM admin on Jun 25th, 2009 on healthdame.com)

PLM patients discuss the past healthcare market relations, and how influentials in the market criticize the value of PLM research:

The practice of medicine is usually top-down. I'm proud to participate, in a small way, in building a knowledge base that can help MSers make informed decisions about their own treatment. I often wonder if you anticipated the number of people who would be on board with PLM...lots of data to crunch...(joycesvoices)

I want the Doctors to go back to the days when there was a patient doctor relationship, where the Doctor knew my name. A relationship that was based on trust. I think the patient should be looked at as a COMPLETE picture and not just the isolated symptoms-which is an argument for the PLM philosophy-it means the patient is seen as a whole and not a piece.(Leddy)

PatientsLikeMe is different than other health web sites. It's not just a research tool. It's a community of patients sharing real-world information about their disease. A lot of the information there can't be found anywhere else. Even the best doctor in the world is limited to the literature she's read, the patients she's treated, and the colleagues she's talked to. There are thousands, if not millions, of other resources that a motivated patient can seek out that is not practical for their medical team, if they're lucky enough to have one smackhacker

I have addressed my problems with sex with my OB/GYN, and I would get the stupidest looks. It's like what? You never heard of this before?? Or the sex would be painful for no reason. I finally did some research and it's Vaginal Atraphy just like muscle atraphy. If it's on the web, why the heck am I being looked at like I am stupid? All the symptoms I was explaining was in the article! Good grief. Jadedangeleyes

Why do most doctors today treat their patients like a number? I've been using the same doctors for years, and for the most part, they don't even remember or know my name let alone anything about me. I always feel rushed during an appointment, especially gyn appts. It's like they have less than 5 mins to spend with you, then they have to rush onto the next patient. Whatever happened to compassion? I do my best to be an informed patient consumer and always bring a list of questions with me....and will not leave the office until my questions are answered. I feel this is my right to know and care about my health and healthcare and I'm paying for a service, not to be superficially examined and hear "see ya next year." (Serialmo)

As an employee of a large medical device company, I know that our technology ultimately improves patient care. Unfortunately, I feel disconnected from the patients that we assist & am excited to learn about technologies that can help patients more directly. I've also been trained to really love data! The combination of real quantitative data, direct patient interaction, community & emphasis on preventative medicine is very exciting. I'll stay tuned to see how you grow this business, improve patient care and help lower health care costs…Thanks…Comment by SW Adams

I'm being left untreated by doctors because of their personal bias. I have not directly been told why I should reduce or discontinue my drug use (despite asking clear and specific questions), only that they don't feel that they should give me medications that can help me. (fragiletrut, mood community patient profile)

I have found it frustrating to get my doctors to talk to each other; to sharing what information they've gleened about my complicated health profile, in order to piece together the larger picture of how best to direct my healthcare. It is of the utmost importance that all of my doctors confer with Dr. Herbst - my quality of life depends on it! It's my Internist and Specialists who get to examine me on a regular basis, something which Dr. Herbst cannot do since she is located in San Diego, CA. Too often I've been told by doctors that they'll contact another of my doctors, but rarely has it happened or that I'm aware of..... In this day and age, IMO, I've found that doctors seem to be afraid to do what they've been trained for. Worried about malpractice or the lack of trust by the government to treat patients with difficult health problems for fear of having their license taken away or having the DEA breathing down their necks. Some of the concerned physicians have, as pertaining to malpractice, would be to be honest and forthcoming with their patients - be it a mistake or withholding information that needs be shared with the patient. (YbNormL, mood community patient profile)

GPs can't keep up with all the new information and specialists are often just looking for test subjects, not patients. Sick people are often caught in the middle. One must be proactive in their own health care cause otherwise you are on your own. With this group you are not only being proactive...but you are not on your own. Good going!(Sherry Drew)

if you have an ongoing medical problem is you need to be in charge of your care. You need to understand your medications and your condition. That is not hijacking anything that is being responsible. One of the best things about PLM is being able to talk to other people taking the same medications you are. One of my medications is administered through a patch. I had some problems with it this winter and I was able to talk to people who had the same sticking issues and get some good advice. My doctor, wonderful as he is can't help much with that. He has the information included in the drug leaflet, he's not wearing the thing. I've never gone swimming with it, the leaflet contains no advice on this issue but Mmama in Georgia has and she can tell me how it worked for her. There has just been a recall of said patch. I heard about it first on PLM. My pharmacist hadn't heard anything yet when I picked up my refill yesterday. I just sent off an email to my neurologist this morning. I will call later today to get instructions for how to deal with this. You can't just stop these powerful drugs. I wish I didn't have to take them at all but they are the reality of life with a progressive disease. PLM helps me manage that aspect of my life better (Tomte2).

I understand that many in the established medical community will view PLM as a threat. Myself, I was scolded by my neurologist for seeking out information on my own. What they don't realize is that PLM offers insight to a disease that you can't learn in any book or from a waiting room full of patients. I learn more from PLM that all other sources of info combined and, more importantly, I have learned to trust that information more than any other. A doctor can only offer his/her opinion, learned though it may be. PLM offers the collective knowledge of thousands of people who have not learned or read about my condition but are living it every single day (SmoothS).

When I changed doctors, I had my records forwarded. Or, at least I thought I did. Someone in a doctor's office decides what is important and what is not, then sends a condensed version of that information. I saw what was in the file at the new doctor's office, and it was only a page and a half. No record of my past colds illnesses, or what antibiotics worked and which I couldn't take. Maybe the lost stuff wasn't important, but if it was important enough for the original doctor to write down and save, why isn't it important enough to forward? Its my medical records, not theirs! (mikelinpa).

I don't have a complete copy of my medical records because the definition of "nominal fee" is open to interpretation by the party I'm asking to provide the copy. So last year when I was hospitalized for three days I was asked to pay $547.93 for a copy of the records that my insurance company and I had already paid for. I have found that what may seem like spare change to someone making six figures a year, for me on my just barely above the poverty level income is prohibitive (emmy).

Hospitals hate to share information. What happens when you're injured and you go to a different hospital than the one that has your information - they have to collect it all over again upon your admission. Not easy if you're incapacitate. Go to http://www.herontech.com/ to see a system for info sharing. It has been running in Jamaica for years with no problems. It was developed by a Canadian company, however Canadian hospitals are loathe to use it as it would affect their individual funding and make their funding mare transparent. Posted by: cinques

If a medical clinic hadn't' lost my medical records and what they said about me at the age of 32 I would not have been able to get help for health problems I had correctly figured out I had in high school. I have Asperger's syndrome which could not be diagnosed in the US before 1994. I also have sleep apnea and am a devout Christian. I figured out one of the reasons I was so tired all the time (the other reason being hypothyroidism) was sleep apnea. But no doctors had heard of it. I thought the shrink they wanted me to see would know about it, "be my friend' vouch that I wasn't a nutcase and arrange to get me real help. It turned out he had never heard of sleep apnea either. :(And he was an Atheist. He started asking me questions about my religious beliefs. I got diagnosed with schizophrenia and put on an antipyschotic. Fortunately I did not get locked up or second hand smoke + the sleep apnea + asthma which I also have + the forced sedation they would have given me to "calm me down' would have caused me to suffocate in my sleep. That schizophrenia diagnosis followed me for years. Doctors would see that and not bother to run any tests but they sure would take my money! After my medical records were lost they started taking me more seriously and I finally got help for the sleep apnea and slowly, for my other many health problems. Many of them I still had to figure out myself and had a time getting confirmed because my autistic 'weirdness" makes medical personal underestimate me. Posted by: OmegaSeeker

Wow, this site is very awesome for someone with one of those diseases. My dad died of Non Hodgkin's T-Cell Lymphoma 12/2004 and the entire time he was sick, it was difficult for him because he didn't know anyone with the same illness. So, the doctor would prescribe something and because his illness was decently rare, the doctor could only give the 'press release' type side effects, not actual experienced side effects from his 1000s of patients and that was at Pennsylvania Hospital (oldest hospital in the US). This would have proved invaluable as a way to connect with others and learn why a medication was prescribed and all sorts of statistics about everything. Very awesome. Obviously, Dugg

"Privacy has been used as an excuse by those who have a vested interest in hoarding this information, the real reason hospitals jealously guard medical records is they don't want to open themselves up to second-guessing from patients—or patients' lawyers. And that lack of openness is making us sicker: With data scarce, there's no clear way for physicians to know what treatments are working for other practitioners. (Jamie Heywood, co-chair, interview with Wired magazine)

As a physician (and patient) myself, I can say that Bill Clinton's strict HIPPA (health privacy laws) are a pain in the butt for both patients and physicians. The reality is that most doctors would be pleased to give their patients access to their own health records. I routinely give all my patients copies of their records and tests. Greater access would also make our jobs easier, and more importantly it would save money on things such as doing repeat tests (that are done because nobody can get ahold of the results of the same test that was already done somewhere else). Hopefully one day the access to health information becomes a whole lot easier for patients and their physicians. Posted by: Agent2828

A Physician taking a critical approach to PLM and social networking in healthcare: This is great but remember the side effects. If someone gets kidney failure or thyroid problems from taking lithium then what will happen ? If they have ALS, things will just get worse - although with ALS, which is a terrible disease, things cant get that much worse. The point is that drugs have side effects - and sometimes fatal and dangerous ones. If patients do their own trials - then they have to take responsibility for it as well. I can see how it can help. As a physician, I can also see how it can turn into a nightmare. peterporter

A Medical researcher is also critical of PLM polluting clinical trials: AMIA is a forum for medical researchers to discuss clinical-facing informatics projects like electronic medical records, doctor decision-support systems, and standards. This year, the event agenda included its first-ever panel on patient collaboration, with PatientsLikeMe presenting on how our members use informatics systems to spearhead original research. I presented a paper co-authored with Michael Massagli chronicling the activity on the ALS site regarding the site-based evaluation of Lithium. Questions about the paper were enthusiastic and challenging as medical researchers contemplated the full implications of patients conducting research outside of the healthcare system. The most provocative comment came from Danny Sands of Cisco who introduced the possibility that while he saw the value of PatientsLikeMe, we may also be "polluting clinical trials" - when patients with rare diseases take experimental treatments before being enrolled in (his) randomized clinical trials. My response was that he and others in the clinical trial world may feel differently if someone he cared for was diagnosed with ALS – a disease where patients have limited time to explore treatment options. As medical researchers, we should be proud of our patients who are taking an active role in their health care; I know I am. people have long experimented with novel, off-label, and alternative treatments (some with and some without their physicians). Barring the few cases that are published in academic journals, these individual efforts only resulted in a tiny group of people learning anything from their experience. By organizing these individual efforts, PatientsLikeMe allows the data to be pooled and recorded systematically for analysis. Of course, randomized clinical trials (RCTs) are the most rigorous means to systematize experimentation, but they have their draw-backs. They are expensive to run, time consuming (they take years, our study took months), and may be subject to more confounds than their organizers would like to believe. (Jeana Frost, PLM research scientist)

From where I sit, doctors, scientists, researchers, etc., simply don't seem to understand the urgency that one with an chronic illness feels. As an MS patient, I want to be functional and productive as long as I possibly can. I cannot begin to understand the panic that an ALS sufferer must feel. While MS is probably not going to kill me anytime soon, ALS does not have a long shelf life and patients want some help and they want it fast!! Comment by Anne

Polluting clinical trials"? What a funny term. I agree with Jeana, having a chronic disease imparts a sense of urgency to your life that means you really don't want to wait for a few years for a possible treatment, you want it now, or better yet, yesterday. Clinical trials are a distant hope, not a real world solution for many people. The ability to try something that may (or may not) work opens the patient's prerogatives so much more than passively waiting. Comment by Laurie

I am a patient with MS, and active in the PLM community. My time there invaluable. If it were not for this community, my quality of life would still be horrible, and I mostly house bound. But now, I am looking to get off disability and go back to work, as I have been offered a job. This, a feat I never thought possible. Now my unused Master's Degree and training will be put to use. To PLM, thank you. What I have learned from PLM that has improved my quality of life, is, I now take a better drug for pain, spasticity, and fatigue. All drugs I am currently on for these symptoms, never were offered to me during my six years living with MS after diagnosis. This due in part to my inability to adequately describe my symptoms, and part due to my doctors inability to think outside the box from what he defaulted to using. But with more information, knowledge and understanding, communication on both sides improved and I got the help I needed. This only due to PLM. For it is there I learned to describe my symptoms better, and from there I shared with my doctor other treatments. With a little time, he became more open, and I communicated better. I also changed my vitamins, learned stretching exercises to help with pain due to spasticity, etc. I in turn shared experiences of low sugar intake, low intake of bad fats, rest, and managing stress, etc. As we all have shared the ins and outs of our daily routines, we make adjustments from what we learn on PLM. This greatly improves our quality of life as well. Add the support element, and the loneliness of living with a chronic disease lessens. That is priceless. If all this can happen in small part, improving ones quality of life, just imagine this process taking flight in the scientific community. The success of the individual then spreads to the whole of the group. We all, patients, doctors, and the whole medical community is lifted up. If there is fear because the process is outside the box, well I say there in lies the hope for progress. For those who are sick, the benefits far out weigh the risk. Because in the end, it is the quality of life and enjoying ones time with loved ones that matters. Medical advancement and all that goes into that, gives us the ability to enjoy our lives and our families. Comment by Cindy Hiel

The outright stubborn old thinking ways of many researchers and doctors is quite frustrating to many people of chronic diseases, the openness of individuals with what works for them and alternatives available to others is invaluable to me at least. I was informed and joined a normal clinical trial, and through that information others did as well, would the trial have received as many people in it as it has without PLM? possibly but would have taken much longer to do so in my opinion. Many doctors get upset even if told of patients coming to this community, that aspect boggles my mind, most doctors spend 5-15 minutes every few months with patients unless serious issues arise, yet expect patients to sit there miserably in between and manage miserably? that is infuriating to me, I tell my doctors right off the bat I am in this community, if they have issue with that then they are not looking at my best interests imo. Many folks here have little to no support outside of online community, that in itself is beyond compare. Doctors and researchers need to quit being so self centered (yes I know with some that is impossible) and think of the best for the patient…you know the one paying the bill…Comment by Nick

Regarding clinical trials, they have their place in all things medical. However, I suspect that the majority of MS victims live in areas where participation in trials is not a viable option. Additionally, exclusionary rules prevent many others from signing up for a trial. PLM has provided us with a means to help ourselves, especially when our doctors are overbooked, overwhelmed, minimally knowledgeable, and firmly in the pockets of the pharmaceutical industry. I have watched as PLM members gain confidence, become assertive and proactive with their medical providers, and FIGHT to receive the proper care. I have also watched the PLM family members make huge changes in their lives–diet, exercise, vitamins, spiritual———all because of the knowledge and support offered on this site. I believe that as sites such as PLM (none better, by the way) proliferate, the medical community is going to HAVE to take notice and will begin taking patients more seriously. Empowered and knowledgeable people can NOT be blown off!!! Comment by Connie

It's fantastic to hear from everyone on this issue and hear about your experiences. I still cannot believe how many people are changing the course of their care – getting educated about their condition, finding promising trials, learning how to get the best treatment, and yes finding a doctor that will help them do so. I think a lot of these individual efforts are invisible as they happen one person at a time - it's great to learn about them here together to know how it can be done. And no matter what physicians and researchers do, the tide is not changing. Patients are involved. Providers and researchers can resist patient participation but ultimately, I think knowledge will be best served when researchers engage this growing group of informed and insightful individuals. Comment by jfrost

Anyone who knows me knows that I am truly an advocate of patient engagement. I applaud patient communities and am excited at the prospect of patients sharing information about the management of their illnesses to the betterment of all. I am also excited that PLM even has a research staff. My comments at the AMIA meeting do not negate any of that. Randomized controlled clinical trials are the best way to arrive at the true efficacy of most interventions. That said, they are expensive and difficult to do and sometimes are even unethical. For this reason, other study designs are used, with expressed limitations and are followed, when possible, to formal RCTs. When we skip the RCT, we often get misled about efficacy of an intervention. A recent example was when an RCT disproved the supposed benefits of hormone replacement therapy in post-menopausal women that we learned from cohort studies. Although I welcome patient-initiated research, we must be careful about calling the studies done through patient communities "clinical trials" for the following reasons: 1. There is no objective assessment of clinical endpoints, which can mislead us. 2. Interventions can cause harm as well as benefit. Sometimes there may be subjective improvement but actual harm being done (due to disease progression or toxicity). A clinical trial tracks both objectively, and safety issues are (usually) identified by a safety monitoring committee without a vested interest in the study outcomes. In patient initiated studies we do not have this safety monitoring. 3. The reason that RCTs are blinded (so that subjects do not know if they are in the intervention or control group), is to avoid them perceiving a benefit just because they want there to be a benefit (the placebo effect). That will then bias the results towards showing a positive impact when none exists and therefore giving us an inflated impression of the impact of the intervention. 4. Once patients have been exposed to an intervention, they often do not qualify for inclusion in an RCT. In the case of common conditions, like diabetes or heart disease, this is not a problem. In the case of a more rare disease it can be impossible to conduct an RCT, which would be devastating to the advancement of medical science, and could lead to continued ignorance of the real impact of interventions. Moreover, prohibiting these patients from participating in RCTs would be disadvantageous for them, as well. I find the work of patient communities like PLM fascinating and important for hypothesis generation. I also understand that desperate patients want answers and do not want to wait for well designed clinical trials to be performed. I am not suggesting that this work should not be done, I'm only concerned about our being comfortable accepting these trials as strong evidence of efficacy. These studies can lead to important hypothesis generation. These communities can also be tremendous sources of subject recruitment for RCTs. The purpose of my probing at AMIA (and of this post) is to educate the community about the importance of formal clinical trials and the role and limitations of patient community run trials. I think PLM and other communities would do a great service to their communities by doing the same. Comment by Danny Sands

I'll heartily verify Danny's statement about how patient-centered and empowering he is. I experienced it years before I got sick, it played out from the first moment of bad news, and has continued since then. At the same time, I have to say I have multiple, complex concerns about the process by which trials are conducted *and reported* to us, and the ensuing questions about whether we the patients can count on them as the best possible pathway to saving our butts. (N.B.: I did not just say I don't like clinical trials! I'm pointing to limitations of the system, not saying it's trash.) In my recent post about evidence-based medicine I said "On the fringes of medical knowledge, lives are at stake and medicine doesn't have the answers yet. What do you do?" The e-patients white paper mentions Danny's work. It also mentions "the lethal lag time" - the lengthy period (more than ten years!) from conception of a research project through its execution and publication. One source said it's 17 years from conception until findings are actually in use in doctors' practices. Many many people can die while waiting for that. As I've discussed with Dr. Sands, having responded well to an extreme treatment (in a clinical trial), I'm now upgraded to where I only have a 50/50 chance of relapse in my lethal disease. So am I sitting passively, waiting? No, I'm doing what I can to improve my odds, through diet and anything else I can find that even MIGHT improve my odds. And then there's the reality that clinical trials are extremely costly so a trial never even happens on something that doesn't have big money behind it. (This is not a complaint against companies in general - I'm just talking about a limitation of clinical trials.) As Anticancer points out, raspberries have clearly been shown to have anticancer properties, but try to find RCTs about their effects. (That's especially ironic because unlike most new potent treatments, raspberries aren't likely to lead to long-term side effects.) The importance of that issue is shown by the very existence of PLM. If commerce could be counted on to produce things like PLM, it wouldn't have needed to arise on its own, out of the patients. Finally, Chapter 5 of the e-patient white paper is titled e-Patients as Medical Researchers and talks about groups of patients collecting their own data. I presume that if that paper were written today, PLM would be a prime specimen. (And remember, it's Danny's team who wrote it.) All in all, while I fully agree with the value of a good RCT, I myself would not hold myself back from something I believed was good for me, just so I might be a purer specimen a few years down the road. All I can say is, power to the people - the patient people. Let's just do everything in our power to educate ourselves and be proactive in creating the best possible odds for ourselves. To me that includes understanding both the value and the limitation of clinical trials - and open conversations like this. Comment by e-Patient Dave

Thank you for your comments Danny and Dave. First off, I want to say I respect Danny's work as a patient advocate and thoughtful physician. So, I just wanted to clarify a couple of things. I didn't understand the comment of "polluting clinical trials" as a reflection of the empathy of a physician to individual patients or a reticence towards patients locating information or support online. Nor, would we describe the investigation on PatientsLikeMe as a RCT or say that RCT's are not valuable. I heard this comment as well, I think a little tongue and cheek but reflective of a larger concern coming out of the clinical trial research world. Danny just happened to be testing that larger view to a patient-centered panel. I heard solely Danny's last point from his comment above - a hint of a deeply felt and understandable anxiety that patients, if they begin to take off-label drugs of their own initiative, will not be available as test subjects. And I do understand that concern. Facilitated by the Internet, an increasing number of people with the interest/resources/wherewithal to find new treatments and with the willingness accept risk, will experiment on themselves - especially when there is no trial available. But, I also think this concern is problematic. Can we really argue for patients to hold off treatment in order to remain eligible for a future possible clinical trial? Instead of viewing this phenomenon as a threat, I think we at PatientsLikeMe see it as an opportunity – a challenge to revisit and revise medical research methods as patient-centered. The question for me/us is where do we go from here? How can patients and researchers take advantage of the efficiency of patient-led work to create new knowledge? How can patients and medical researchers best coordinate efforts, analyze the data, and interpret the results? What are the possibilities and the limitations of this work? These are open questions. While we are at the beginning of this effort, we have promising early results and the next generation will be better. The goal is to design new experimental patient-centered research methods such that the resulting data will be informative - as well as patient-centered, nimble, efficient, ecologically valid, and inclusive. Comment by Jeana Frost (PLM research scientist)

Great dialogue and an important issue for patients (I know if I had a life-changing illness I'd be looking up every trial in the world to see if I was eligible!). Danny is a well-known patient advocate and his reputation speaks for itself; that said, if a physician with his appreciation for the value of online communities has reservations then we obviously still have further to go in engaging people in the debate. Something that hasn't been mentioned yet is just how few patients, even at specialist centers, are eligible for traditional trials. A recent study of the leading ALS centers showed that only 1 in 4 patients were ever enrolled for a clinical trial (Bedlack et al 2008). There are a number of studies cited within that paper that point to an enrollment rate of less then 5% in cancer patients. So if you are not eligible for a trial, what are you to do? Remain a "clean specimen" for a small chance of getting on to an RCT (after which you've got a 50/50 of being on placebo of course!)? We fully appreciate the difficulty, the complexity, the passion and the energy that goes into setting up and executing a clinical trial, and perhaps if we can do a better job of referring on those patients who we know will be eligible, we can avoid "polluting" these trials. But we also have an equal if not greater level of responsibility to offer opportunities to the vast majority of patients who will never be asked to take part in research studies. I firmly believe that research participation is an intervention in itself, particularly in serious conditions like ALS, and it's something we should be able to offer more patients. Comment by Paul Wicks (PLM staff)

Paul brings up an excellent point. Although some of the low enrollment is due to knowledge and availability (knowing a study exists and having access to it) it's also due to stringent enrollment criteria, so that we know we are studying subjects that are as similar to one another as possible. This makes the results more valid (but at the expense of generalizability to broader populations). So we certainly need a way to reconcile this dilemma. I don't have the answers. One thing is certain: in addition to providing information to people with serious illness, we must teach them how to find and enroll in relevant clinical trials, and help them learn about the advantages and disadvantages of all forms of clinical research. Every clinical research methodology has it's advantages and disadvantages (validity, generalizability, bias, cost-effectiveness of conducting trial, etc.). I need to consider study design when deciding whether a particular study influences my care of patients, and patients should consider this when deciding whether to start an unproven treatment (as well as the risks and benefits of participating in a trial). This requires a fair amount of sophistication, but it is incumbent on us to help educate patients–as physicians, support communities, or patient website creators. Comment by Danny Sands (Physician)

In response to people like Mr. Sands, I would say that while rigorous clinical trials are necessary, they also remove options and control from patients. For example the Fingolimod trial has restrictive controls on what patients can have taken in the past and currently and also on patient profiles. This removes many people from the pool of subjects and removes this as a treatment for many many more. I was not eligible for a study because I do not have a complete family medical history. While I understand that this is how trials work, it is hard to be removed from a treatment option entirely. If I had a rapidly progressive disease, I would be more than willing to flout conventional studies and try just about anything. The establish research methodology (and its practitioners) need to understand that for some people there is not enough time to wait for the establishment to get together a study and recruit people (which may not include them). There is also the fact that the established research community is not interested in many of the treatments (like Lithium for ALS) because the drug is old and off patent. There is no one willing to spend the thousands on a study that at best (if it revolutionized treatment and everyone ended up using it) could net them pennies. They also tend to think very narrowly and pass many treatment ideas. I think PLM allows people to find others like them who are willing to advocate for themselves and butt heads with the medical community if necessary. It has made me far more willing to take an idea to my doctors and at least have them consider it seriously. I can't force them to do anything, but because PLM has made me my own health advocate, neither can they force me to do anything. Comment by Marie

Problems with Traditional Clinical Research: We also must consider the consequences of waiting for more information. For someone with a life expectancy of several years, the consequence is obvious. Unfortunately, the harsh reality is that the traditional medical research system will not provide any better data to patients for at least 2 years – that is, 6 months to start a trial, 15 months of evaluation, and 3 months to share the data. In fact, 2 years is being optimistic, if truth be told. History teaches us that it will most likely be much longer. History also teaches us that patients sharing stories with each other will not answer the question alone. Chinese stem cells, herbal supplements, nutraceuticals — all have been discussed extensively on the internet with some claiming cures and some describing great harm; yet we have no definitive answer. Despite the thousands of postings, very little knowledge has advanced the treatment of ALS, and patients are still left unable to make effective treatment decisions. there are also systematic flaws in the disjointed way that trials take place which makes it difficult to get accepted into a trial and can make participation unsatisfying even if you do. Say you've got ALS (Lou Gehrig's disease or Motor Neurone Disease), a progressive and incurable life-changing illness and you're being treated at a specialist centre that runs a lot of clinical trials. Here's a few scenarios that could happen: The Drug X trial is full before you can participate. The Drug Y trial is only looking to recruit a specific subset of patients so you're not or The Drug Z trial is an existing drug being used off-label. After taking the drug for 12 months your rate of progression has been slowed significantly and you wish to continue taking the drug. Although the study gets published in an academic journal, it's not taken that seriously because it wasn't a double-blind randomized control trial. If patients are willing to continue taking a treatment off-label with the agreement of their primary care physician, the use of an outcomes-sharing site like PatientsLikeMe provides an ongoing opportunity to monitor adverse events and perhaps even evaluate efficacy at little cost (bearing in mind the caveats and biases of such an approach (Paul Wicks, support)

(Ken Patterson) I have been tracking and sharing my progress on lithium since March. My ALS has stabilized and the side effects are minor compared with the benefits I see. "The problem with waiting for a larger study is [that] time is something ALS patients have little of…If my information benefits scientists in finding a treatment or a cure, even after I die, then it was worth the sharing of personal information.

The medical establishment, in fact, has taken way too much time to understand that the Internet is a disruptive innovation that has overturned the status quo. It has leveled the playing field between expert and novice -- in this case, doctor and patient. While some doctors like Haig may find that challenge threatening to their status as an expert, the Web is now providing the kind of information doctors need to be aware of if we want to continue to be good at our job, and the kind of trends that can help patients be smarter and healthier. Patients who, prior to a visit, consult information online can better share in the decision-making process with their doctor. Afterward, they can go online to find information that reinforces their decision or introduces them to viable alternatives. Today, there are many accurate, high-quality health sites, and doctors should make it a standard practice to recommend them to each and every patient. Besides reducing the randomness of a Web search, this can reinforce a physician's advice during a visit, which is especially helpful, as studies show that patients typically remember no more than half of what their doctor tells them. (Dr. Rahul K. Parikh)

There is enough information that I can always check out any medicine if someone says it works, bad information is rife in brick-and-mortar medical settings. Leonata Good, PLM Parkinson community

I do have a question about reliability of self-reported data. In my case, I never really understood the mechanisms for data entry despite at least 2 requests to admin for help; there does not appear to be a comprehensive "help" manual. Do other people have trouble logging their symptoms and general disease history? Symptom descriptions are all over the place--the same symptom can be described in many ways. My data is not completely accurate, and I don't know how to fix it. Is there a help manual on the way? Joycesvoices

We don't plan a help manual, but try to include tips on the pages, along with our site FAQ. If it needs explaining it should be in the FAQ. Symptoms are a special challenge for us. We provide a list (588 and counting) but understand that we may not have them all, so allow people to add their own. This leads to some of the similarity entries you see. It'd be better if people went with a more general term, but some folks want very specific symptoms. Makes it challenging to aggregate, but that's the trade-off we've made. We do curate this list, and actually just finished doing so recently, but it's hard to keep on top of it. From your comment I get that we need to try harder. Got it. So don't worry about complaining - we can't fix it if we don't know it's broken (or near broken). Let us know. We appreciate it. Tim (admin)

I don't think that self reported data are all that reliable, but if certain trends are seen then it could point towards things to look at with more reliable data gathering methods that might not have been thought of to look at before. (uhoh)

In regards to data integrity, we are constantly working on mechanisms, both technical and community based, to ensure the safety and accuracy of our data. Because the data we are collecting are patient-reported outcomes and treatment regimens, PatientsLikeMe represents what is happening in the real world. However, we always need to recognize and reduce any bias that our patient-reported data may have. In order to ensure quality of data, we just implemented data quality grading of patients where users earn stars for filling out their profile, keeping their information current, and tracking periodically over the course of their illness. We are beginning to track equipment models so patients can learn which specific brands work best. (Ben Heywood, founder)

What makes our data unique is that every data point is backed by clinical or functional outcomes data from real patients. Everyone can compare and evaluate progress, thus understanding the context of treatment utilization. This accountability creates a much more credible set of information. Releasing this data can also help neurologists and other physicians learn how colleagues are prescribing a particular medication. Doctors can see the distribution of dosage ranges as well as side effect frequencies on numerous medications. It's a great way to keep abreast of the latest prescribing trends. Paul Wicks, support

How reliable is the information about symptoms and treatments? Like all information you come across, on the web or elsewhere, it is important to carefully compare it against many other sources. Our symptom and treatment reports reflect data that have been entered by the community. They cannot be guaranteed to be accurate, and they are not intended to represent complete information about a treatment, symptom, or disease. (from PLM website FAQ page)

Unlike a blind placebo control trial, we are watching the use of this drug in the real world, and because of the number of patients and our system's sophisticated data modeling, we can determine the significance of each reported change in each patient as he/she deviates from his/her predicted course. There are many risks to our approach, patient optimism, the placebo effect, uncertain quality, and many other variables will compromise our data. Despite these, and many other challenges, we remain committed to solving this problem. ((James Heywood, co-founder)

Patientslikeme is a critical step in our ability to gain more real-time insight into the evolution of treatments and outcomes. Until we have a robust health information infrastructure that allows clinicians to have more real-time feed back that is not just office visit based we will continue to have rather limited insight on true healthcare outcomes. To characterize the right of individuals to share their health information with whomever they choose as a "regulatory escape clause" is a bit disconcerting. HIPAA in fact made it a Federal law that individuals have the right to access their information and always allowed use of the information with patient consent. Unfortunately few patients realize their rights, the process to obtain the information is not always easy or electronic and the format and comprehensibility of the information is rarely patient friendly. We need to foster the efforts of these patient-driven initiatives not only to support improved patient care, but to foster patient engagement which may be our greatest key to improved health care quality and services. Shannah Koss

BIOGRAPHICAL SKETCH

Handan Vicdan earned a Ph.D. degree in Business Administration with emphasis in Marketing at the University of Texas-Pan American in August 2010. She graduated with Bachelors of Art in Communication Public rRelations and Advertising in 1998 from Ege (Aegean) University in Turkey. She then worked for Novartis Pharmaceuticals as a medical sales representative. In 2005, she earned a Masters degree in Business Administration from the University of Texas-Pan American in Edinburg, Texas. Her research stream includes studies of social, cultural, and technological transformations in how consumers (re)organize their lives and become producers of their experiences in actual/virtual theaters of consumption; specifically issues of consumer freedom, body, power, resistance, the effects of online media technologies on consumer literacy and consumer-marketer collaboration, and implications of social networking in healthcare. She has published in numerous journals such as Journal of Customer Behavior, Journal of MacroMarketing, and Journal of Virtual Worlds Research, and in conference proceedings such as Association for Consumer Research, Academy of Marketing Science, and American Marketing Association.