FROM BOUNDARY-MAKING TO BOUNDARY-BREAKING?
MEDICAL KNOWLEDGE PRODUCTION, THE INTERNET & NEW LAYERS OF POWER

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ABSTRACT

As access to medical information increases, patients and medical professionals begin to engage in negotiations of power. These behaviors directly challenge and shape the process of medical knowledge production, as well as notions of expertise. With new forms of expertise, additional power dynamics occur between medical professionals and patients.

The relationship between the medical professional and the patient shifts overtime, as each attempt to control the ways in which medical practices work. Inherent in initiating one’s agency compliance comes into play. Traditionally, the non-expert (the patient) follows the recommendations of the expert (the physician): patient-compliance. However, as medical information becomes more accessible, compliance can shift back and forth between patient or lay-compliance, expert-compliance, and even mutual-compliance.

Research suggests patient self-education encourages the emergence of a new informed patient. Current trends in patient online health searching, for instance, suggest a growing population of proactive patients. These proactive patients engage in activities that challenge traditional notions of medical expertise. Research in patient activism also examines the ways in which patients can acquire and comprehend medical knowledge ordinarily possessed by those within the medical community (i.e. AIDS activism during the 1980s and 90s). Many patient activists have and continue to influence various medical institutions; and more crucially,
practices of medical research. However, there is a lack of research connecting the dots between the informed patient, the Internet, and the work of clinical research.

In this thesis, I focus on boundary creation: the specific practices individuals engage in as a means of constructing and deconstructing barriers of access. Barriers of access include: 1) the opportunities to participate in the production of medical knowledge and 2) the ability to acquire and disseminate medical information. Many forms of medical knowledge production establish walls between the medical professional and the patient: instances of what I call boundary-making. Through an historical analysis, I show instances of boundary-making, as American physicians transition from societal “quack” to medical authority figure.

However, where walls are made, walls can also be broken. In instances of boundary-breaking, I argue that increased access to medical information enables the medical professional and/or the patient to participate in the process of medical discovery and understanding. As a more diverse set of actors begins to contribute to medical knowledge production and dissemination, expertise becomes ambiguous. Through a grounded analysis of two case studies, I highlight instances of boundary-making and breaking in the context of: 1) a patient-initiated research foundation, the Amyotrophic Lateral Sclerosis, ALS Therapy Foundation, and 2) the 2005 launch of the online data-sharing platform, PatientsLikeMe.com. These two sites each showcase how boundary-making and breaking can occur in complex and often complicated ways. In introducing these concepts, I hope to encourage readers to rethink what it means to conduct medical research in the Digital Age.
The research and writing of this thesis is dedicated to my Gram: the self-proclaimed A.A.D., whose passion, wisdom and love inspire me everyday.

JESSICA BETH POLK
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**INTRODUCTION**

PatientsLikeMe.com: an online data-sharing platform where patients voluntarily upload their personal medical history in order to compare their health to the health of others in similar situations. With 15 condition-based communities and approximately 70,000 patient participants, PLM members range from those suffering from ALS (Lou Gehrig’s disease), HIV/AIDS to mood disorders like depression. It was in the HIV/AIDS community that PLM encountered an interesting act of protest. At the time, nearly half of its members decided to remove all of their data from the platform. After all, they owned it. The reason behind this pull: PLM would not take down a derogatory comment posted in the HIV/AIDS community forum. The website would not comply with the wishes of these patients. As the website depends upon patients’ data, these members knew the exact button to push: delete (Udell, 2009). Their data became leverage, where notions of compliance were challenged and access to information controlled.

What does this example say about the current dynamics occurring between medical professionals and patients? With access to their personal health information, patients can enact a certain level of agency and control over their health and its management. Furthermore, by taking ownership of their data, some patients are able to control how their medical information is used. As with this event on PatientsLikeMe.com (PLM), patients are beginning to determine whether they want: 1) to share their medical information with other patients, 2) to provide their data to clinical research or 3) to remove, or rather, delete their medical history from an online database all together. As patients begin to take ownership of and make use of their personal health information new forms of agency and power can emerge. Interesting boundaries begin to surface.

When it comes to health, many patients justifiably turn to the medical professionals, the experts, for advice and treatment recommendations (Fox & Purcell, 2010). However, the medical
expert is slowly shifting—no longer embodying one particular individual, institution, or community. As communication scholar Deborah Lupton argues, patients are increasingly taking initiative over their health (Lupton, 1997). Based on increasing trends in patient health-related Internet use, patients engage in proactive behaviors regarding their health and the type of care they desire (Fox & Jones, 2009). Patient online health information sharing and patient-generated medical knowledge production directly impact the current state and position of the medical professional. For instance, with patients sharing their health information online via platforms such as PatientsLikeMe.com questions pertaining to the patient’s role in medical knowledge production arise. The traditional notion of the medical expert becomes fuzzy. If “patients think that doctors cannot provide the emotional support and personal interest they feel they need, then they may seek treatment from other kinds of practitioners” (Lupton, 1997, pp.378). But, who are these “other practitioners”? What new types of experts are patients seeking out? As medical information becomes more accessible (i.e. the Internet) does expertise become more achievable for those not traditionally considered a medically trained professional?

Expertise becomes complicated when both medical and patient communities engage in practices of what I refer to as boundary-making and boundary-breaking. As such, this thesis focuses on boundaries: the demarcations between medical professionals and patients. Boundaries do not represent literal walls that separate informed experts from uninformed patients. Rather, boundaries act as barriers of access. First, these barriers include access to the process of medical knowledge production, or the practices of discovery that become medical fact. Additionally, barriers of access also include the availability of specific medical information. Information accessibility (or lack thereof) enables certain individuals to understand aspects of the body,
disease and treatments options available. This research’s emphasis is not that boundaries exist, but rather, the process of boundary-making and breaking. How a diverse set of actors make and break boundaries of access. The focus of this research is the practices individuals choose to take on as a means of constructing and deconstructing barriers of knowledge-based and informational access. Historical and social factors contribute to the individuals granted to the opportunity and access to participate in the production of medical knowledge.

Boundary-making extends Thomas F. Gieryn’s boundary-work (Gieryn, 1983). In boundary-work, Gieryn examines how scientists intentionally employ discursive practices through public dialogue. Scientists use these discursive practices in an effort to separate their work from the work of others (i.e. those institutions they deem non-scientific, such as religion). Focusing on the relationship between medical professionals and patients, I argue that experts are not the only individuals creating boundaries. Both “experts” and “non-experts” can intentionally and unintentionally build boundaries—attempting to establish credibility and expertise within the medical system and the public at large. On that note, I assert that individuals to do not always intentionally create boundaries. Unintentional practices and activities can also initiate instances of boundary-making as well.

Moreover, creating boundaries involves more than just intentional discursive work. Certain activities can facilitate instances of inclusion and exclusion with regards to medical knowledge production and access to medical information (Bowker & Star, 2000; Epstein, 2007; Reiser, 1978). The use of certain technologies and specific techniques of information gathering can also create a divide between those in a medical encounter. Thus, I propose boundary-making: instances that enable certain individuals to see, hear and understand a patient in ways this patient
may not be able to know him/herself. By using a stethoscope, for instance, the physician hears
the patient’s lungs and acquires certain information about the state of a patient’s body that
facilitates the diagnosis process. Yet, the patient rarely hears his/her own lungs. It is only through
the physician’s account or secondary-information that the patient obtains information about
his/her prognosis. While boundary-making generally involves the actions of experts (the medical
professionals), instances of patient-generated boundary-making can also occur. As with the
opening example, the HIV/AIDS patients on PLM built a boundary by establishing a barrier of
access to their health data. By deleting their data, these HIV/AIDS PLM members blocked PLM
researchers and their industry partners from viewing, using and profiting from their health
information.

Building off of boundary-making, I define boundary-breaking as instances in which medical
professionals, patients or both gain access to medical information. With this access, each
community has the opportunity to participate in or even contribute to the process of medical
knowledge production. For example, patient online health-information seeking behaviors can
facilitate instances where patients begin to understand their bodies in ways they never could
before. In the case of PLM, patients can compare their medical record to the medical records of
thousands of other patients suffering from the same ailments, conditions or diseases. Exchanges
of this nature rarely, if ever, happen within the traditional medical setting (i.e. a doctor’s office).
Opportunities to see the medical records of other patients are unique examples of boundary-
breaking that occur online. However, as the opening example illustrates, in breaking down
boundaries, boundary-making can emerge as well.
In introducing boundary-making and boundary-breaking, I highlight specific negotiations that arise between medical professionals and patients as each attempt to establish their own sense of expertise. These negotiations involve challenging processes of knowledge production (i.e. who produces the knowledge, where production occurs, and the knowledge deemed worthy of universal acceptance and credibility). Correspondingly, negotiations also surround the extent to which certain individuals have access to medical information. With these negotiations of power and expertise, challenges regarding compliance surface. As power dynamics evolve, those individuals required to adhere to the recommendations of another begin to shift.

In breaking down the act of negotiations and the barriers of access between medical professionals and patients, one must first understand the three variables that come into play: 1) medical knowledge production, 2) information accessibility and 3) compliance. I define medical knowledge as the actual process of medical discovery and the results that eventually become medical facts. For instance, the discovery of bacteria and its impact on the human body resulted in this known fact: bacteria can make you sick. Those acquiring medical knowledge engage in specific practices, like medical training or laboratory studies. Those individuals participating in these practices (predominantly, medical professionals) acquire a holistic and extensive understanding of the body, disease, and treatments. This broad knowledge contributes to the very making of a medical expert. With expert status, individuals determine the type of medical information disseminated to the public, as well as, the extent to which the public can access this information. Information consumers or those outside of the production process (namely, patients) must depend upon accessibility in order to become medically informed. While medical knowledge represents a broader scope of specific practices of discovery and understanding,
medical information is narrower in form. In this research, medical information represents specific facts: the data obtained from the process of knowledge production. As such, medical information depends upon access. I define access as an individual’s ability to obtain specific pieces of information that allows this individual to understand a symptom, a disease, or treatment options.

In this process of becoming medically informed, both medical professionals and patients confront issues of compliance. I refer to compliance as the extent to which certain individuals adhere to the wishes and advice of others. Within the medical context, compliance generally focuses on the patient: whether a patient follows the recommendations of their medical professionals. Hence, the commonly used phrase patient-compliance. Extensive amounts of literature examine the ways in which patient-compliance influences the validity of medical research, especially within the realm of clinical trial work (Barry, 2005; Boys et al., 2003; Davis et al., 2002; Epstein, 2008; Freedman et al., 1980; Gades et al., 2006; Marcellus, 2004; Moser et al., 2000; Robinson et al., 2007; Slymen et al., 1992). As access to personal health information increases and patients begin to share this information with others (as with PLM), compliance can shift.

Therefore, compliance plays a key factor in practices of boundary-making and breaking, with compliance representing aspects of individual control and agency. Shifts in compliance allow for various individuals to influence and, at times, determine which facts are included and excluded from the larger body of medical knowledge. The importance of compliance to this research rests in its ability to influence the work of medical knowledge production and information accessibility. That is, compliance influences: 1) where medical research puts its efforts (the
participants involved in a study), 2) where (or the place in which) knowledge is produced, and 3) where medical research is heading (the very structure and practices of medical research). The extent to which patients, participants or even medical professionals adhere to the rules inherent in medical work and practices impacts the kind of information produced. Patient and physician compliance can determine what we know, and in turn, what we do not know about health, the body and disease.

With regards to compliance-based negotiations, Kristin K. Barker examines a new form of compliance emerging among patients with contested diseases. In her analysis of one online support group for Fibromyalgia sufferers, Barker highlights instances of physician-compliance. In physician-compliance, patients with diseases like Fibromyalgia, “belie[ve] that their shared embodied experience trumps the presumed ‘expert’ knowledge of doctors” (Barker, 2008, pp.28-9). Additionally, these patients:

[D]efine the ideal doctor as one who unquestionably acknowledges patient expertise, and they attribute non-compliance to doctors’ lack of knowledge. There is an expectation that doctors will concur with patients’…definition of the situation (i.e., they have a discrete physical illness) and the definition of the solution (i.e. they need a fibromyalgia diagnosis and access to the host of medical treatment recommended by fellow sufferers) (Barker, 2008, pp.31).

Within the context of websites like PLM, however, instances of boundary-breaking facilitate more than just physician-compliance. Physician-compliance, for instance, can also include a much broader expert set including clinical researchers and even pharmaceutical companies. I introduce expert-compliance as a possible extension of Barker’s physician-compliance. Additionally, instances of mutual-compliance can also occur. In mutual-compliance both medical
professionals and patients each comply with the specific needs and recommendations of the other. Lastly, patient-compliance can still exist, even as medical professionals and patients engage in mutual and expert–compliance. Just as experts are asked to comply with the demands of patients, often times, patients still have to adhere to the rules and recommendations set by the professionals. As such, where boundaries are broken new demarcations can be made and variations of compliance surface.

In the chapters that follow, I break the research down into two distinct parts. Part I provides a historical context of the relationship between medical professionals and patient communities (Chapter I and II). Part II applies this contextualization to specific case studies (Chapter III, IV and V).

1.0. **Part I: Understanding Boundary-Making & Breaking**

In order to examine boundary-making and breaking, I first contextualize the concepts. Through a historical analysis of the relationship between medical professions (physicians and researchers) and patients, I explore shifts in place, technique and technology use. Specifically, I highlight how shifts in these three factors (place, technique and technology use) allow for differentiations between the medical expert and the layperson to surface. Place represents the specific location (or locations) where medical knowledge is produced and accumulated (i.e. the physician’s consultation room or a clinical trial). Technique represents the specific strategies and practices used in the processes of diagnosis and treatment (i.e. the role a patient plays during a medical encounter or even the use of medical terminology). Medical technology includes the
technological tools or informational resources used to understand the human body and/or disease (i.e. a stethoscope, X-ray or the Internet).

Keeping particular attention to place, technique and technology use, the first half of this thesis builds primarily upon the research of Stanley Joel Reiser, Paul Starr, Steven Epstein and Henry Jenkins. Chapter I focuses on boundary-making. American physicians engaged in extensive practices of boundary-making (Epstein, 1996; Gieryn, 1983; Goodwin, 1994; Knorr-Cetina, 1999; Star & Griesemer, 1989; Star & Strauss, 1999) in an effort to change their status from societal quack to medical authority figure (Starr, 1982; Shorter, 1985). The physician-patient relationship from pre-modernity (17th-18th c America) to the present has undergone great transformations. Shifts from bedside medicine (Shorter, 1985) and domestic medicine (Starr, 1982) to the clinic and the emergence of the ‘medical gaze’ and a ‘sick society’ (Foucault, 1973; Marcuse, 1967) encouraged the rise of a medical authority figure: the physician. Patient consumerism also marks significant transformations in how physicians and patients interact (Gwyn & Elwyn, 1999; Haug & Lavin, 1981; Hollon, 1999; Holmer, 1999; Lupton, 1997). Generally speaking, the above literature traces the evolution of medical professional-patient interactions over time. I emphasize the transitions that occur from the days of the passive patient to the current rise in proactive patient behaviors.

In Chapter II, I examine boundary-breaking. This chapter provides an overview of the ways in which physicians and patients, as well as, clinical researchers and participants negotiate notions of expertise, compliance and access to medical information. Lay expertise, or what Steven Epstein refers to as “successful lay incursions into biomedicine,” most famously occurred by the actions of AIDS treatment activists in the 80’s and 90’s (Epstein, 1995, pp.409). As AIDS
activists became “genuine participants in the construction of scientific knowledge,” the knowledge gap between the medical expert and the lay patient minimized (Epstein, 1995, pp.409). Through extensive studying of and self-training in medical research (Epstein, 1995), as well as the use of popular mass media (Sturken & Cartwright, 2001), AIDS activists acquired knowledge that facilitated the inclusion of their voice in the very practices and structure of medical research.

Today, medical information is easier to accessible. Patients increasingly utilize the Internet to obtain medical information and advice (Fox, 2009; Hardey; 1999; Jenkins, 2006; Manhattan Research, 2008; Mayer & Till, 1996; Webster, 2007; Goetz, 2010). Patient self-education has generated scholarly debates surrounding control, patient empowerment, and the dangers of patient-generated medicalization (Barker, 2008). That is, in demanding experts to recognize patient expertise, patients can also contribute to the process of categorizing and labeling their own bodies. This process of medical categorization encourages the patient and his/her body as sick and most crucially, something that should be managed and controlled (as with medicalization). Thus, do proactive patients further feed into the medical machine, encouraging patient-compliance? Or do these behaviors open doors to new medical discoveries, unique forms of expertise, and instances of expert-compliance? These questions become key in the analysis of boundary-breaking within two specific case studies: the second half of the thesis.

2.0. Part II: Applying Boundary-Making & Breaking

To understand how boundary-making and breaking occur in situ, I focus my analysis on two empirical cases. The data analysis derives from grounded theory methods that include the coding
and categorizing of interviews, films, articles, and field work (Charmaz, 2006). The first case study examines the development of a patient-initiated foundation, the ALS Therapy Development Foundation (ALS TDF).* The mission of ALS TDF: to find a cure for ALS or Lou Gehrig’s disease. When diagnosed with ALS in 1998, Stephen Heywood had approximately five years to live. His family, and namely, his oldest brother Jamie Heywood, would and could not accept this prognosis. Due to its orphan status (a status given to those diseases with a population of sufferers that does not justify the costs for full treatment development and research), ALS remained incurable. As such, in the hopes of saving Stephen’s life, the Heywood’s started an accelerated research foundation dedicated solely to ALS.

Chapter III traces how this family of lay caregivers broke down the traditional walls of medicine, challenging the practices and procedures of medical research. In their foundation work, the Heywood’s engaged in boundary-breaking (and consequently, boundary-making) practices that provided their cause a sense of credibility and expertise. In the context of the ALS TDF case study, boundary-breaking occurred in a progressive and stage-like manner. For instance, the first stage of the Heywood’s mission involved a personal fight: a personal investment, commitment, and dedication to a specific cause (specifically, ALS). With the personal fight, the Heywood’s determination motivated them to accrue a team. The initial team required individuals willing to engage in unconventional medical research. I refer to this team as mavericks. There are three types of mavericks: 1) the Personal-Amateur Maverick or those with a high personal stake in the cause and little to no medical expertise and experience; 2) the Personal-Professional Maverick or those with a high personal stake and trained skills in

* In 2007, ALS TDF was renamed ALS TDI: The ALS Therapy Development Institute (http://www.als.net/AboutUs/TenYearAnniversary.aspx).
scientific and/or medical work; and 3) the Professional Maverick or those interested in the novelty of conducting research outside of the confines of academia or industry. Once a team is established, the foundation needed to enroll the medical system at large. They needed to market their mission. In the final stage of boundary-breaking within the context of the Heywood’s foundation, marketing a mission transforms the personal fight (i.e. to save Stephen Heywood) into a larger or more universal cause (i.e. to save all those patients suffering from ALS).

Throughout each stage of boundary-breaking, the making of boundaries also occurs. As lay individuals attempt to establish their expertise they simultaneously challenge the expertise of others (namely, experts within the ALS community). This very process of making boundaries in the process of breaking them becomes even more evident in the analysis of the second case study.

As referenced in the opening example, the second case study examines the Heywood’s next venture: a patient-generated data-sharing platform called www.PatientsLikeMe.com (PLM). In Chapter IV, boundary-breaking is complicated as various actors (patients, PLM researchers, and industry partners) enact a certain sense of control and agency over the use of patient medical data. It is in this case study that information access, and the barriers that inhibit actors to obtain certain types of information, becomes crucial. Through extensive ethnographic and grounded theory work (in-depth interviews with PLM employees and field work at the Boston-based company headquarters), I highlight the complexity of boundary-breaking. As my data analysis shows, by contrast to the stage-like progression of boundary-breaking in the ALS TDF context, boundary-breaking within PLM represents a complex mixture of power dynamics and negotiations surrounding ownership, control and compliance.
Launched officially in 2005, PLM currently houses a total of 15 disease/condition communities, each categorized as based on disease/condition prevalence and rarity. The conditions range from the rare and terminal (i.e. ALS) to the more common and chronic (i.e. mood disorders, such as depression and post-traumatic stress disorder) As of November 2010, membership totals over 70,000 patients choosing to voluntarily share their detailed medical history on PLM. Some members opt to keep their profile and information private, visible only to those within the PLM community. While others, approximately 10,000 members, take a more open approach—sharing their profile to both PLM members and non-members. In creating a PLM patient profile, patients must select the condition/disease community to which they belong. Once selecting a condition-specific community, members go through a series of quantitative condition-specific surveys and questionnaires, reminiscent to those one might find while sitting in the waiting room of a physician’s office.

While membership is free for the patients, PLM profits by charging clients (primarily in the pharmaceutical industry) for access to anonymous PLM member data. With the inclusion of industry, power negotiations expand beyond just medical experts and lay patients, but also lay patients and lay experts (the researchers at PLM). As lay experts emerge, new layers of power surface. For instance, in recoding and selling patients’ self-reported data, PLM creates an additional barrier between the patient’s voice and the medical industry.

As access to medical information increases (i.e. online health information), new types of experts begin to contribute to the process of medical knowledge production. With a larger number of experts challenging and entering the medical system, new layers of power develop. And additional boundaries materialize. In making and breaking these new boundaries,
negotiations of control, ownership and compliance inevitably occur. This research hopes to illuminate how these shifts in medical information accessibility directly influence the relationships between physician and patient, researcher and participant. These changes have and will continue to shape not only medical expertise, but also the ways in which credible and trustworthy medical information is produced and universally accepted.
CHAPTER I
BOUNDARY-MAKING: THE BIRTH OF THE MEDICAL AUTHORITY FIGURE

1.0. Introductory Comments: On Boundaries, Experts & the Lay

Historical and social factors contribute to and shape the very practices of medical knowledge production. In turn, medical knowledge production influences the dissemination and ultimate accessibility of medical information. Those individuals with the opportunities to contribute to the production and dissemination of medical knowledge obtain a certain status of expertise. This status facilitates the expert-lay divide. Through a historical analysis of the rise of the American physician, this chapter explores instances of boundary-making. Boundary-making is an extension of Thomas F. Gieryn’s notion of boundary work (Gieryn, 1983). Focusing primarily on science, Gieryn defines boundary-work as scientists’ attribution of selected characteristics to the institution of science (i.e. to its practitioners, methods, stock of knowledge, values and work organization) for purposes of constructing a social boundary that distinguishes some intellectual activities as ‘non-science’ (Gieryn, 1983, pp.782).

Boundary-work emphasizes scientists’ efforts to differentiate their expertise over other forms of practice-knowledge, such as religion, which these scientists’ deem non-scientific. Specifically, Gieryn argues that this work is conducted through rhetorical practices of public discourse. In boundary-making, I expand Gieryn’s argument to the medical setting, arguing that boundary-construction involves more than just intentional discursive practices.

Boundary-making involves specific practices and activities both experts and non-experts engage in as a means of creating demarcations. These demarcations represent the boundaries between the informed (those with the ability to produce medical knowledge and disseminate
medical information) and the uninformed (those who must depend upon others for specific forms of medical knowledge and information access). With a focus on medical knowledge production and information accessibility, I define boundary-making as both the intentional and unintentional uses of medical technology and techniques of diagnosis and treatment that enable certain individuals (namely, medical professionals) to see, hear and obtain specific forms of information regarding the body and health. As these individuals acquire information, boundary-making works in ways that exclude others (primarily, the patient) from obtaining information in the same form and type. For instance, within a traditional medical encounter (i.e. a doctor’s office), the medical professional gets to know the patient in ways the patient is unable to know him/herself (i.e. the sounds of a patient’s lungs via the use of a stethoscope). It is only through the physician’s interpretation of the information he/she obtains via medical technology (i.e. the stethoscope) that the patient comes to understand his/her own body.

The making of boundaries depends largely on three factors: 1) place, or the specific location (or locations) where the production and accumulation of medical knowledge occurs; 2) technique, or the specific strategies and practices employed in the process of diagnosis during a medical encounter; and 3) technology or the technological and informational tools and resources used to uncover, assess, and eventually disseminate medical information and phenomenon. That is, the use of specific technologies, locations of medical knowledge production and acquisition, as well as various techniques of medical inquiry facilitate instances of what I refer to as boundary-making.

According to historian of science, Stanley Joel Reiser in *Medicine and the Reign of Technology*, medical technology influences not only “the relation between physician and
patient...[but, also] the systems of providing medical care and treatment” (Reiser, 1978, pp.ix). Medical technology—defined as the informational tools and resources available to understand, diagnose and treat illness and disease—influences medicine as an institution, a methodology (or practice of scientific method), and a profession of human relations and interactions. Reiser emphasizes the importance of technology and technique in the history of medicine and the physician-patient relationship. However, I also emphasize the importance of and interrelated role place (the very location or locations in which medical information and discovery is produced and housed) plays in the practice of medicine. I assert that place directly affects not only the types of medical techniques, practices and technologies used, but also the way in which individuals engage in instances of boundary-making. The power of place in determining who gets to produce and access medical knowledge influences the relationship and power dynamics between (and among) medical professionals, patients, and participants.

The process of medical knowledge production and selective techniques of information gathering and accessibility facilitate instances of boundary-making. Historically, it is through boundary-making that the physician was able to establish his credibility—differentiating himself from other medical practitioners, and most notably, the patient. As such, the below sections examine historical instances of boundary-making in the context of the role American physician play over time. First, I examine the physician as quack, where boundaries placed the patient in the expert role. In transitioning from a quack to a medical authority figure, physicians created boundaries solidifying their position of power. In the era of the specialist and medical consumerism, the physician’s role transitioned into that of a supplier, with patients being a physician’s top customer.
2.0. The Time of the Quack: The Patient as Practitioner, The Doctor as Last Resort

American patients from the 17th up until the mid 19th century, intentionally and unintentionally engaged in practices of demarcation. The use of specific medical technologies and techniques within a selective place granted the patient (and his/her family) with information about his/her body. The doctor could only obtain this information by way of the patient and his/her account. As such, a clear distinction between the knowledge and expertise of patients versus that of the doctor existed. In the time of the medical quack, American doctors relied heavily on the patient when it came to the process of diagnosis and treatment. Referred to as bedside medicine, the patient, his/her family members and loved ones (caregivers) possessed the power in terms of medicinal practices and responsibilities. Patients directly influenced and facilitated the process of medical knowledge production. Thus, knowledge resided within the walls of the patient’s home. In order to engage in medical work, the doctor, in this sense had to be physically invited and granted access to this specific and well-defined boundary.

For the doctor, the patient and his/her narrative represented the primary requirement for accurate diagnosis and treatment. When a physician was summoned, he depended on the verbal accounts of symptoms experienced by the sufferer. Patients’ accounts influenced the doctor’s means of information gathering. As Reiser explains, prior to medical instruments, such as the stethoscope or X-ray:

To determine the nature of illness, he [the doctor] relied chiefly on three techniques; the patient’s statement in words, which described his symptoms; the physician’s observation of signs of the illness, his patient’s physical appearance and behavior; and, more rarely, the physician’s manual examination of the patient’s body (Reiser, 1978, pp.1).
In fact, patient narratives were so trusted that when great distance existed between doctor and patient:

[Physicians often diagnosed illness and prescribed treatment through the mails. Such a practice demonstrates the doctor’s general confidence in the patient’s subjective [and personal] account of his symptoms, as described in a letter, as well as the doctor’s willingness to forego personal observation of the patient in arriving at a diagnosis (Reiser, 1978, pp.6).]

Unlike their selectively trained and elite British counterparts, American doctors were not referred to or even granted the title ‘physician.’ This label, which bestowed its owner with a certain level of credibility, authority and prestige, had to be earned. The physician represented those select individuals that “had presumably learned in medical school how to prescribe physic, or drugs” (Shorter, 1985, pp.27). Prior to the establishment of clinics and American medical schools, doctors were considered quacks. J. Marion Sims best illustrates this quack status in a memoir published in 1885, entitled The Story of My Life (referenced in, Shorter, 1991). In the following 1832 excerpt, Sims recounts his father’s reaction to Sims’ medical career choice:

‘My son, I confess that I am disappointed in you…I suppose I cannot control you; but it is a profession for which I have the utmost contempt. There is no science in it. There is no honor to be achieved in it; no reputation to be made, and to think that my son should be going around from house to house in this country with a box of pills in one hand and a squirt in the other…is a thought I never supposed I should have to contemplate’ (Sims qtd. in, Shorter, 1991, pp.54).

Medical education (or lack thereof) is an important fact to acknowledge, as medical training, while present, was at a minimum in the American colonies. By contrast, British physicians’ reliance on and alliance with prominent and highly respected institutions, such as the Royal
College, established a physician’s position and power within British society. Places of medical training—the university—played a large role in establishing the medical expert. The selectivity and prestige granted by these places of training created a distinct boundary between those considered experts and those considered quacks or lay. Historian of medicine, Paul Starr explains that while a handful of American colonists around the mid-to-late 18th century took the initial steps to reproduce the professional institutions that in England gave physicians a distinct and exclusive status...Before the twentieth century, American physicians found the path to professional status blocked by popular resistance (Starr, 1982, pp.30).

But, why was there such a “popular resistance” to the medical professional?

In what historian Edward Shorter refers to as the traditional doctor, Americans viewed doctors as a danger to both society and their patient clients. If summoned, American doctors were considered the last resort in the process of healing a patient (Shorter, 1991). Guided by the values of Christianity and Protestantism, Americans during the time of the medical quacks, regarded religion as the primary source of enlightenment and nature as the powerful product of God. Disease and illness represented a divine sign: the “proper reaction to an accident or illness [for Americans] was to search one’s soul for moral error…they also often took illness to be a sign of God’s displeasure and warning to the dissolute” (Starr, 1982, pp.35-6). Similar to patients, those that practiced medicine also placed a great deal of importance on religion. The process of diagnosis and treatment predominantly rested in the hands of fate. For instance, despite the fact that doctors were asked to:

[T]ry to cure the patient…such remedies were to be employed cautiously, with the recognition that they could only work if God permitted. [While,] it was lawful to take physic [drugs], [it
was] unlawful to trust in it too much...Health came from God, not from Doctors (Starr, 1982, pp. 35-6).

Like religion, nature also played a crucial role in the practice of medicine. Prior to urbanization during America’s Industrial Revolution of the late 19th century, the majority of Americans concentrated in rural areas and exercised an agrarian lifestyle. Therefore, medical interventions were largely grounded in the healing power of nature: the herbal remedies and plants found in one’s own backyard. Reliance on herbal remedies and the techniques and technologies of the home marked a time of domestic medicine (Starr, 1982). With domestic medicine, the American family acted as the center of medical care. More often than not, the woman’s role in the household also included acting as the family doctor. It was their moral role to care for the health and well being of their family members (Starr, 1982, pp.32-3). Domestic medicine placed patients, and namely, their women caregivers at the center of diagnosis and treatment.

While place, technique and the rudimentary technologies in the times of domestic medicine favored the patient as expert (the physician as quack), urbanization and the move from an agrarian lifestyle to an industrialized one proved to impact these three components greatly. As Michel Foucault argues in The Birth of the Clinic: An Archeology of Medical Perception,

[M]edicine becomes a task for the nation...abuses would be prevented and quacks forbidden to practise [sic], and, by means of an organized, healthy, rational medicine...Good medicine would be given status and legal protection by the state; and it would be the task of the state ‘to make sure that a true art of curing does exist’...a quite new form, virtually unknown in the eighteenth century, of institutional spatialization of disease, makes it appearance (Foucault, 1973, pp.19-20).
Boundaries shifted as physicians began to establish their own practices of demarcation: engaging in their own strategies of boundary-work between their expertise and the practices of non-experts (the patients, religion, and domestic medicinal practices) (Gieryn, 1983).

3.0. The Age of the M.D.: The Professional as Practitioner, The Patient as Subject

The Industrial Revolution, during mid-to-late 19th century America, provided the once doctor “quack” with the opportunities and resources to establish his authority, legitimacy, and power over medical practices and knowledge production. American doctors acquired the official M.D. title of “physician” through their direct association with selective institutionalized and clinical training. Transitioning away from the patient’s comfort zone (namely, his/her home), medicine became an institutionalized practice. To practice medicine was to diagnose and treat in a specific and new place: the clinic. This modern location provided the medical professional with a certain form of power. This power, consequently, influenced the type of techniques and medical technologies used for purposes of medical discovery and clinical diagnosis.

Foucault argues that the modern university and hospital established an institution of formal medical training that generated selective and exclusive bodies of medical knowledge. The very walls of the university, hospital and clinic established distinct boundaries between new medical experts (those within the walls) and lay patients (those who resided outside). The clinic endowed modern physicians with a powerful medical gaze over their patients (Foucault, 1973). Thus, the objectification of the patient transformed this once the vocal human participant to the sick subject of medical inquiry. This objectification took a variety of forms: 1) spatially, a regulated and confined place of medical knowledge production, 2) a displacement of patient as a human
being to patient as the object of disease, and 3) new techniques of discourse and specialized terminology. With regards to place,

For clinical experience to become possible as a form of knowledge, a reorganization of the hospital field, a new definition of the status of the patient in society, and the establishment of a certain relationship between public assistance and medical experience, between help and knowledge, became necessary; the patient has to be enveloped in a collective, homogeneous space (emphasis added, Foucault, 1973, pp.196).

Boundary-making by way of a new clinical space (the clinic) encouraged the formation of a new patient type, who had to be managed and collectively categorized within a specific “homogeneous space.” That patient (a de facto boundary) could be broken down, allowing the physician to talk directly to the disease. With techniques of physician-disease communication diagnosis could occur without the patient’s interpretation. In the modern medical encounter:

[The physician] is dealing with diseases that happen to be afflicting this or that patient: what is present is the disease itself, in the body that is appropriate to it, which is not that of the patient, but that of its truth…the patient is the subject of his disease, that is, he is a case; in the clinic, where one is dealing only with examples, the patient is the accident of his disease, the transitory object that it happens to have seized upon (Foucault, 1973, pp.59).

Thus, it was the voice of the disease that mattered. The disease’s narrative (as represented in its visible and/or audible symptoms) became more salient than the patient’s account. This new discursive technique propagated the creation of boundaries between expert and lay, observer and observed. The clinic and hospital paved way for “a reorganization in depth, not only of medical discourse, but of the very possibility of a discourse about disease” (Foucault, 1973, pp.xix). By
contrast to bedside medicine, which relied on the *effects* of disease, clinical medicine emphasized the *causes* of disease:

‘What is a matter with you?’, with which the eighteenth century dialogue between doctor and patient began (a dialogue possessing its own grammar and style)…was replaced [with]…‘Where does it hurt?’, in which we recognize the operation of the clinic and the principle of its entire discourse (Foucault, 1973, pp.xviii).

The patient became the subordinate “deviant” or “other” and the physician the dominant “agent of social control” (Haug & Lavin, 1981, pp.212). Through specific medical techniques of questioning during a patient consultation, the physician engaged in boundary-making between himself (as expert) and the patient (as sick and lay).

The development of specific medical technologies also encouraged instances of boundary-making. Technologies such as the stethoscope, the X-ray, the microscope and the diagnostic patient record each played a large role in modern medicine and the physician-patient relationship. With the stethoscope, for instance, physicians heard the body for the first time:

[A] new technique—mediate auscultation…made it possible for the physician to detect chest disease in living patients by studying the character of the sounds the damaged tissues produced (Reiser, 1978, pp.23).

The sounds heard from the stethoscope provided (and still provide) the physician with information that the patient did (and does) not receive in the same form. The physician obtains information via direct sound from inside a patient’s body, while the patient receives the physician’s interpretation of that sound. Both the physician and the patient acquire a certain level of medical knowledge, however, the type of information differs greatly between the two. The X-
ray enabled physicians to see the body in a new light. When introduced in the late 19th century, X-rays

[D]irectly challenged the use of touch in diagnosis. Before their discovery, doctors had evaluated fractures by manually probing the injury...[However, with this technology,] the surgeon could locate the position of the bones easily, and reassess their alignment after putting on the cast (Reiser, 1978, 63-4).

These technologies reinforced the sick role model, as physicians no longer needed the patient’s account of symptoms to understand the insides of his/her body. Furthermore, the use of these technologies in a specific place (the clinic rather than the patient’s home) reduced the number of cues and the type of information the physician had to sift through in order to effectively diagnose and treat.

Through the use of technology, the body could be made to speak for itself. In these instances of boundary-making, technology provided physicians with literal mirrors into a patient’s body. Physicians could “know” the patient in ways the patient could not. Interestingly, these technologies allowed for the physician to break down the boundary that once existed between the patient and the disease. This, in turn, created a new boundary between the physician and the patient. For the patient these technologies acted as metaphorical mirrors (Turkle, 1995)—whereby that patient only receives a second-hand or interpretative account of what the physician saw or heard (the literal mirror).

4.0. “Show Me the [Drugs]”: The Specialist as Supplier, The Patient as Consumer

Advancements in medical technology and techniques of diagnosis and treatment did not stop at instruments such as the stethoscope or X-ray. New discoveries in drugs and pharmaceuticals
proved to be another medical technology influential in the power relations between physician and patient. Medicine during the 20th century marked a “Drug Revolution” (Shorter, 1985). New medications and drug therapies strengthened the physician’s position of power and his/her ability to treat and cure illness. As noted by Edward Shorter:

[The] early 1950s would see drugs that fought inflammation…Drugs that work on the heart and lungs, on disease of the central nervous system like Parkinson’s disease, on parasites, on cancer, on schizophrenia, on hormonal imbalances causing infertility…The effect on doctors was to imbue them with a relentless new enthusiasm about their ability to cure organic disease (Shorter, 1985, pp.182-3).

The ability for physicians to prescribe medication reinforced instances of boundary-making. Only the trained physician truly understood the chemical compounds being prescribed. Thus, a selective group (the trained physician) possessed an understanding of how these medications worked and when the treatments should be prescribed.

Correspondingly, medication could only be accessed and distributed within the walls of a selective place (the hospital, the doctor’s office, and eventually, the pharmacy). To obtain a written prescription, patients must visit the physician on his/her own terms and on his/her own place of work.* America’s Drug Revolution changed the very practice of medicine and the specific techniques employed. These changes influenced the type of medical education and training physicians received, as well as the type of exchange occurring between the physician and his/her patient. Starting as early as the 1950s, specialized medicine rose in popularity. To be

* With the Internet, however, the accessibility of prescription medication via black-market and/or international eCommerce websites changes the dynamic and power of place, as it becomes easier to obtain once exclusive and restricted prescription medications. In these instances, boundaries are broken and the medical professional is bypassed altogether.
a Primary Care Physician (PCP) or General Practitioner (GP) did not have the same appeal as training to be an internist. Physicians trained in internal medicine were trained much like chemists. “[I]nternists were equipped par excellence to know about drugs. And a public that wanted ‘nothing but the best’ flocked to them as guardians of the new pharmacopoeia” (Shorter, 1985, pp.182-3). In this sense, not only did the medical professional become more specialized, but the patient also shifted into a medical consumer.

Trends in laboratory tests conducted also increased after World War II. The medical consultation became less of an assessment and more of a quantitative transaction. Reiser explains, “from the mid-1950s through the 1960s, some hospitals reported that the number of laboratory tests ordered per patient doubled every five years…” The use of ‘routine’ or ‘baseline’ tests is almost universal [during this time], and the category is ever expanding” (Reiser, 1978, pp.159). This focus on organic disease, drug interventions and diagnostic testing paved way for a “trend toward depersonalization and dehumanization of the care of the patient (Lepore, 1982, pp.3). As such, the boundary between physician and patient becomes more apparent. Medicine became less of a practice of human relations and more of a service of exchange. Exchange also proves to play an interesting role in the clinical study setting. In exchange for your data, the expert might find you “the cure.”

5.0. Boundary-Making & the Clinical Study

The medical researcher (comprising a variety of medical professionals, including physicians themselves) also established legitimacy by creating boundaries. The very essence of clinical work is to test hypotheses on clean subjects: subjects that adhere to the strict protocols and
requirements of a given study. In this sense, *participant-compliance* (a variation of the commonly used term, physician-compliance) ensures the effectiveness, accuracy and validity of clinical studies and trials.

The researcher-participant encounter involves, for the most part, medical techniques and technologies that facilitate boundary-making. More often than not, a clear distinction between investigator (researcher) and investigated (participant), knower and known, active expert and passive subject exists. The researcher sees and understands components of a clinical study or trial that the participant never sees or knows in the same way. For instance, participants are largely unaware of how their information is interpreted throughout the course of a study or trial. They are often vaguely aware of their position/state in the context of fellow participants. Furthermore, they are often unaware of the treatment regimen they have been placed on, as in the case of blind and/or double blind studies. Lastly, many participants are never fully aware of the actual risks that could potentially be associated with participation, especially with a clinical drug trial. In explaining his experience with running clinical trials in ALS (or Lou Gehrig’s disease), Dr. Paul Wicks, Research & Development Director of PatientsLikeMe.com, states the following:

> Patients, when they take part [in a study], frequently either think they are directly contributing to the cure, whatever that may be, or they think that they’re going to get better by participating…[W]e did a lot of clinical trials in ALS. About half of the clinical trials killed the patients faster than placebo. And I’ve never seen an explanation as to why that is. But, you know no matter how many times a clinical trial for ALS would say ‘This probably isn’t going to work, don’t get your hopes up…’ They would, they would believe in the opportunity to do that, either because they thought the treatment was going to make them

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*In the case of a double blind, randomized clinical trial, it is important to acknowledge that the researchers are also unaware of the treatments of the participants.*
better or disappointed when they found out that they were on placebo, which statistically the better place for you to be, in an ALS trial, is on the placebo because then you’re probably going to get better care than somebody who is not on the clinical trial because you’re getting monitored more. **You’re getting a lot more attention, and whatever nasty, toxic drug the treatment group is on, you’re not getting.** And if it does turn out that it [the tested drug] works, they’ll find out pretty quickly and hopefully they’ll switch you onto it. But the likelihood that the drug will work is unfortunately low (emphasis added, Wicks, qtd. in Polk [interview], 2010, pp.3).

As indicated in the above statements, what participants rarely understand is the treatments tested in a clinical trial have yet to be FDA approved. The purpose of a trial is to test and verify whether a treatment is *not* “nasty” or “toxic.”

Strict study protocols and scientific methodologies represent two tools that both intentionally and unintentionally facilitate instances of boundary-making. Protocols allow for researchers to ensure that: 1) a patient qualifies for participation, and 2) the objectives of the overall study design are met. But, as Dr. Wicks’ implies, protocols (and tested drugs) are not necessarily in place for an individual participant’s personal benefit. Rather, protocols are in place for the benefit of the study and future patient populations. According to Appelbaum et al., in “False Hope and Best Data: Consent to Research and the Therapeutic Misconception,”:

The use of a study protocol to regulate the course of treatment—essential to careful clinical research…impedes the delivery of personal care…Protocols often indicate the pattern and dosages of medication to be administered or the blood levels to be attained…adjunctive medications or forms of therapy, which may interfere with measurement of the primary treatment effect, are often prohibited…[Thus,] there is always a chance that the subject’s interests may become secondary to the demands on the physician-researcher’s loyalties. And
the methods of science inhibit the application of personal care (Appelbaum et al., 1987, pp.20-1).

However, it is not necessarily the existence of protocols, or even the lack of “personal care” that raises concerns. Instead, it is the lack of participant understanding surrounding the entirety of study protocols, and how little participants realize the consequences these protocols may have on their well being that raise the most concerns. By restricting the amount and type of information a patient obtains when participating in clinical research, boundary-making occurs. Certain individuals are more informed (the researchers) than others (the participants).

While participants are given an explanation of study protocols during both the enrollment phase and the subsequent “Informed Consent Form” process, a large majority of these participants “systematically misinterpret the risk/benefit ratio of participating in research because they fail to understand the underlying scientific methodology” (Appelbaum et al., 1987, pp.21). This misinterpretation results in therapeutic misconception. Therapeutic misconceptions largely occur in the context of a randomized blind-study. As Appelbaum et al. argue, most participants of a randomized and blind study believe that their assigned treatment plan is based on their individual needs and specific circumstances (Appelbaum et al., 1987). This of course is not the case, it rarely is. Disclosing certain information to the participant, especially with regards to the treatment they have been given, would not only create bias in the results, but would also encourage instances of participant retention (i.e. would a participant want to stay in a study knowing he/she is on placebo?). Boundary-making in this sense represents a necessary practice.

The essence of boundary-making is how the use of technology provides certain groups of individuals with a distinct type of knowledge that at the same time excludes others from
acquiring that same form of information. In this sense, protocols become double-sided mirrors (neither literal nor metaphorical), allowing for the researcher to see and know certain things about participants, while making it difficult (if not impossible) for the participant to see and know the same. While “the scientific method is a powerful tool for advancing knowledge…like most potent clinical procedures it has side effects that must be attended to” (Appelbaum et al., 1987, pp.24). Protocols, grounded in the scientific method, act as the tools that mask distinct types of information from the patient.

However, they exist for important reasons: they ensure a clinical study or trial is valid and applicable to patients in the future; they enable researchers to control as many variables and eliminate the greatest number of biases. Ironically, however, these very protocols and the confined place of the clinic visit also facilitate interesting forms of boundary-making that do not benefit the experts. Blinded by the double-sided mirror, the researcher sees and comes to understand a specific aspect of the patient base, disease and treatment under study—a clear boundary between what is seen in the trial versus what actually occurs outside of the laboratory walls emerges. As referenced earlier, Reiser’s words carry an even greater meaning in the context of clinical research: “Each fact-gathering technique uncovers a particular component of the disease picture, different in some ways from that revealed by another such technique” (Reiser, 1978, pp.227). Accordingly, clinical trials, with its specific techniques of information gathering and knowledge production, often times, only provide one side of the disease coin. For instance, what happens within the controlled walls of a clinical drug trial might not accurately illustrate what happens outside of those walls.
6.0. Concluding Remarks: The Emergence of Boundary-Breaking

Both historical and social factors influence shifts in the place or location of medical discovery (from the patient’s home to the institutionalized clinic or doctor’s office), medical technologies (from the patient’s narrative to the sounds and images of disease), and techniques of diagnosis and treatment (from domestic remedies to diagnostic tests and pharmaceuticals). These shifts directly influenced (and continue to shape): 1) the type of medical expert (a quack versus a physician), 2) the type of patient (a vocal narrator versus a subject of medical inquiry), as well as 3) the ways in which credible and trustworthy medical knowledge is produced and universally accepted (fate in divine interventions and fate versus results produced from controlled clinical studies grounded in the scientific method). Boundary-making allows for individuals (those considered experts) to engage in both premeditated and unintended practices, whereby information is disseminated in a variety of ways and formats as based on one’s position of power, access and expertise. Correspondingly, it is through boundary-making that power, access and expertise are gained.

As the examples over time illustrate, boundary-making takes on many shapes and forms in numerous contexts: ranging from the use of a stethoscope to discursive practices of medical terminology (within the physician-patient consultation), and even study protocols that mask certain aspects of a participant’s role in the context of a clinical study or drug trial. Nevertheless, where there is boundary-making, instances of boundary-breaking can potentially follow. Often times, these processes of making and breaking are in fact co-dependent. As individuals work to break down divisions between experts and lay, these same behaviors can, at the same time, encourage new forms of demarcations and boundaries to materialize.
Thus, within instances of boundary-breaking, boundary-work can arise, as “ideological practices with a certain style” arise as medical experts “attemp[t] to create a public image for science [or their specific type of expertise] by contrasting it favorably to [what these experts deem to be] non-scientific intellectual or technical activities” (Gieryn, 1983, pp.781). Deep in the crevices of demarcated walls between expert and lay one can find instances of negotiations of power and knowledge production. As the next chapter indicates, boundary-breaking further complicates what it means to be an expert in matters of health and well being. What we deem to be the traditional medical expert (i.e. the physician or clinical researcher) is not the only boundary maker. Patients can also engage in the blurring of boundaries between what they know and what the medical community ‘thinks’ they know. Without boundary-making, boundary-breaking would and could not exist.
CHAPTER II
BOUNDARY-BREAKING: THE NEW MEDICAL EXPERT(S)

1.0. Introduction: The Emergence of Boundary-Breaking & A Convergence Culture*

The use of specific technologies, shifts in place or locations of medical knowledge production, and techniques of medical inquiry facilitate instances of not only boundary-making, but also instances of what I refer to as boundary-breaking. Boundary-breaking describes instances in which place, technology use, and specific techniques of medical discovery encourage both the medical professional and the patient to participate in the process of medical understanding. As tools of boundary-breaking, current trends in patient technology usage and new techniques of information gathering provide patients with the opportunity to see and know their body in ways a medical professional can. Certain platforms give patients a front see view, a VIP pass, inside his/her own body and health trajectory.

According to Henry Jenkins, our convergence culture illustrates how we increasingly embrace and utilize a type of “media convergence, participatory culture, and collective intelligence” for our own personal pleasure and benefits (Jenkins, 2006, pp.2). Although Jenkins’ focuses on our relationship to entertainment-based media outlets, the goal of his work is to highlight how we will soon see shifts in the power of collective information sharing via media channels, such as the Internet “for more ‘serious’ purposes…chang[ing] the ways religion, education, law, politics, advertising, and even the military operate” (Jenkins, 2006, pp.4). However, Jenkins’ argument can be extended to medicine (Lupton, 1997). Jenkins’ concept of convergence encourages distinct forms of technique and technology use that work to displace medical knowledge

* (Jenkins, 2006).
production from a selective place (i.e. the hospital, clinic, doctor’s office, or medical library) to multiple places (i.e. the Internet).

As historian of science, Stanley Joel Reiser argues, medical technology shapes not only the physician-patient relationship, but also the type of information gathered:

Each fact-gathering technique uncovers a particular component of the disease picture…present[ing] the physician with a particular view of his patient and his patient’s illness. However, the technique chosen does more than generate a particular kind of fact—it influences human attitudes and relationships (emphasis mine, Reiser, 1978, pp.227).

Thus, the impact of new medical technologies is not solely that they exist to diagnosis and treat; but, also how individual actors make choices about when, where, and how to use these technologies that result in the greatest influence. Contrary to Reiser’s argument, current trends in technology use (including the Internet) do not only provide “the physician with a particular view” (Reiser, 1978, pp.227), and set of knowledge. But, technologies are now beginning to provide the patient with a specific view and understanding of his/her body as well.

The sections that follow unpack boundary-breaking by tracing its emergence historically: from past instances of patient empowerment and activism to our current culture of convergence (Jenkins, 2006). Furthermore, by focusing on instances of boundary-breaking, this chapter illustrates that in breaking down boundaries new boundaries can emerge. These processes of making and breaking the expert-lay divide are complex, and thus, dynamic in nature. As such, does expertise accessibility truly facilitate collaboration or convergence between the medical community and the patient population? Or does increased access just facilitate another layer of power—yet another brick in the expert-lay wall?
2.0. Boundary-Breaking? The Physician-Patient Relationship

The patient contributes to shifts in boundaries just as the medical professional. Over time, the relationship between the physician and the patient became more of a business deal. The medical encounter transitioned into a bargaining and negotiating of goods between supplier (the physician) and a consumer (the patient). Starting primarily in mid-to-late 20th century America, a distinct consumer-oriented trend among patient populations surfaced. This trend encouraged the public to start to take charge of their own health just as patients did in the earlier days of domestic medicine (Starr, 1982; Shorter, 1985). Specific groups of patients, such as health activists, began to question the practices of medicine and the knowledge medical institutions produced. This retroactive shift back to patient control (at least in the eyes of certain patient groups and activists) took the form of both proactive consumerism and health-activism. Historian of medicine, Edward Shorter, compares patients of the 20th century and agrarian America (Shorter, 1985). Noting that the former began to revert back to characteristics common of domestic medicine. Self-regulation became the standard of patient health care and medical intervention.

Unlike domestic medicine’s sole reliance on remedies in one’s own backyard (herbal and plant-based interventions), patients of post-modernity proactively sought out physicians when they felt a need or desire for pharmaceutical therapies. However, like domestic medicine, the majority of patients only consulted a physician primarily when powerful and potent drugs were considered a ‘must-have’ (in the patient’s opinion). Referred to as the Drug Revolution (which emerged predominately during post-World War II America), the “internists’ share of all physician ‘visits’ more than doubled from 1966 to 1980, and internists…”[became] the ‘family
doctor’ of as much as a third of the elderly population” (Shorter, 1985, pp.194). Patients proactively sought out these specialists, as they were the one’s that possessed the knowledge and exclusive access to the latest in drug discovery and therapies.

The Drug Revolution also inspired many health-activists, the most notable being the AIDS activists of the 1980s and 90s. AIDS activists were determined to get an equal representation or sample of the AIDS community within clinical trial research. Like proactive consumers, *treatment activists* took on the responsibility of “polic[ing] the whole process” of drug therapies and their efficacy, the scientific method and the structure of clinical research “and offer[ing] their own interpretations of [study] methods and outcomes” (Epstein, 1996, pp.32). They demanded a certain sense of control over their own health, with of course, different motivations and techniques. The plight of the AIDS activist group during the 1980s proved to be one of the largest and most successful instances of collective action: unveiling the holes within medical knowledge production and medicine itself. “In the late 1980s ‘treatment activism’ emerged as the forward wedge of the multifocal AIDS activist movement in the United States, wildly hailed—and sometimes damned—for its ingenuity, brashness, aptitude, and muscle” (Epstein, 1996, pp.32). These activists would in fact show that formal medical training, and clinical practices (grounded in the scientific method) are not necessarily a requirement in acquiring and understanding expert medial knowledge. Initially, lay expertise entered sociological research predominantly in the context of activism and social movements.

Cases such as the AIDS movement, represent just one of the many arduous efforts employed by patients and activist groups. To democratize and equalize power relations between the expert
and lay communities, during the 1980s and 90s, involved a rather challenging and time-consuming effort.

3.0. Boundary-Breaking? The Clinical Study Setting

In Steven Epstein’s work, “The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials” he shows how one compelling group of activists successfully made “lay incursions into biomedicine” (Epstein, 1995, pp.409-10). These incursions directly and significantly impacted:

[T]he cultural authority of science and medicine…the public reception of scientific claims…the boundaries between ‘science’ and ‘society’…the relationships between doctors and patients…and the tension between expertise and democracy within complex and differentiated societies (Epstein, 1995, pp.409-10).

The knowledge gap between the medical expert and the lay activist increasingly minimized. Activists became “genuine participants in the construction of scientific knowledge,” and thus, had the ability to “effect changes both in the epistemic practices of biomedical research and in the therapeutic techniques of medical care” (Epstein, 1995, pp.409-10). Through extensive self-training, AIDS activists acquired a certain level of medical knowledge allowing them to discuss topics and utilize discourse ordinarily employed by those within the medical community.

However, an important component of the AIDS activist movement also surrounds this group’s ability to excite and empower the public. As explained by communication scholars Marita Sturken and Lisa Cartwright, AIDS activists utilized their newfound expertise to influence not only the medical community, but also the public at large. To effectively reach the public, AIDS
activists utilized popular mass media. Through media, activists were able to encourage the public to view science (and medicine) critically, by producing a:

[A] large body of visual images that address[ed] the structure of science and the role of the media in reporting on scientific issues…[Specifically,] [t]he work of ACT-UP (AIDS Coalition to Unleash Power) in the 1980s and 1990s introduced a whole new era of political visual culture…ACT-UP’s visual campaigns, which included performances, sit-ins, videos, and posters, were an important venue for the distribution of accurate information about AIDS transmission at a time in history when science and medicine were not working to get out the message (Sturken & Cartwright, 2001, pp.307-8).

As indicated in the above excerpt, popular media played a large role in AIDS activism. Media use directly impacted two distinct groups of “laypeople”: the AIDS activists themselves, as well as the public at large. The role that popular media played in the cause of the AIDS activists is an example of how technology use can effectively blur the boundaries between science and society, the expert and layperson, and the physician and patient.

Nevertheless, medical knowledge production and instances of boundary-breaking (as with the case of the AIDS treatment activists) still resided predominantly in the hands of the medical expert and the physician community itself. Activists and consumers still had to acquire knowledge on the physician’s terms. That is, the public still had to utilize medical libraries for credible information, medical terminology as a form of persuasive discourse, and even a doctor’s visit to treat and cure disease/illness.

4.0. **Collective Knowledge Sharing, Convergence & New Forms of Boundary-Breaking**

The treatment and health activists of the 1980s and 90s spent a large amount of time studying and accumulating “previously obscure and inaccessible medical information” (Hardey, 1999,
Currently, however, patients need only to look as far as a television set or a computer screen (Hardey, 1999). In our current convergence culture (Jenkins, 2006) medical information accessibility (via such media platforms as television and the Internet) allows for unique instances of medical knowledge production: production that involves actors outside of the traditional medical community walls. With the simple push of a remote control, or the click of a computer mouse, the public is able to easily find information that was once difficult (and painstakingly time-consuming) to locate. Correspondingly, patients have opportunities to be actively involved in the production of medical knowledge. Treatment activists (and increasing trends in online behaviors) pave way for a rise in a new form of medical expert: the patient researcher.

The essence of the convergence culture surrounds the way in which the public utilizes the information of popular media (and technology, such as the Internet), as well as “collective (multi-faceted) intelligence” to educate itself on matters of health. This self-education indirectly, and at times, directly challenges the traditional medical expert. It is not the purpose of this paper to disregard the importance and credibility of the physician, but rather, to shed light on the possibility that knowledge no longer has to reside in one distinct location or within one particular authority figure.

4.1. The Connected Patient: American Media Use & Internet Health-Searching Trends

To see the impact of popular media, we must recognize the extent to which our current society depends upon media and technology as not only a form of entertainment, but also a platform for self-education. According to communication scholar, Kimberly N. Kline: “the average person is likely to spend about 84 hours reading magazines, 165 hours reading newspapers, 480 hours accessing the Internet…and/or 1,248 hours watching television” (Kline, 2003, pp.557). What is
of even greater importance in Kline’s research is the following statistic: “The average American is likely to spend less than an hour per year in a doctor’s office” (emphasis added, Kline, 2003, pp.557). Clearly, American’s spend the majority of their time consuming media.

While one cannot assume that all of this consumption surrounds topics related to health, one can make the argument that information via media is more accessible (and in some cases, more desirable) than information obtained directly from an expert, and in the case of health, the doctor.

Americans do not need to look far when it comes to health-related information. For instance, pharmaceutical advertising has been on the rise: as early as 1998, Direct-to-Consumer Advertising (often referred to as DTC) “accelerated since the FDA changed its guidelines in August 1997” (Kline, 2003, pp.557). In a study conducted in 1998 by Prevention Magazine (in collaboration with the FDA), it was found that (Prevention Magazine, qtd. in Holmer, 1999, pp.380-81):

- Over 53 million patients consulted their physicians about various medications they had seen and heard about through DTC-related advertisements.
- Similarly, an “additional 49 million sought information [about health and medicine] from another source, such as the Internet” (Holmer, 1999, pp.380).

Moreover, in a 1999 article in JAMA, Alan F. Holmer cites that over “50 consumer magazines about health care appear on the newsstands every month…[And] nearly one quarter of the Internet is devoted to health care information” (Holmer, 1999, pp. 380). If media and the Internet were this pervasive nearly ten years ago, imagine the impact they have now.

According to the Pew Internet & American Life Project, as of 2008, 61% of American adults seek out health information online (Fox & Sydney, 2009). This percentage is in stark contrast to
the numbers just eight years ago, with only 25% of American adults in 2000 using the Internet to access health-related information (Fox & Sydney, 2009). This growing group of online information-seekers is often referred to as ePatients (Fox & Sydney, 2009).

Literature suggests that online health-related behaviors do affect a patient’s emotional and physical wellbeing (Fox & Sydney, 2009; Fox & Purcell, 2010; Wicks et al, 2010; Barker, 2008; Frost et al., 2008). A large proportion of ePatients utilizes the Internet for information on potential treatment options. As of 2008, 55% of adults have looked online for information about at least one of the following three types of health treatment: prescription or over-the-counter drugs, alternative treatments or medicines, or experimental treatments or medicines…58% have weighed at least two methods of treatment” (Fox & Sydney, 2009). The significance of these trends rests in the fact that for many ePatients health-related information found online impacts their treatment decisions (Fox & Sydney, 2009). As Bo Young, the Publisher and Editor of the journal White Crane, as well as an HIV-positive patient, argues:

We are all lab rats in this experiment with HIV. No doctor has the magic pill and no one knows what’s going to happen next…it isn’t a choice between EITHER western medicine OR complimentary or ‘alternative’ medicine…it’s an increasingly vast buffet table and you should pick and choose from all of it and take care of yourself and what makes you feel comfortable and good. Listen to your doctor as your advisor, but YOU are the final arbiter about what is good for you and what isn’t. There is no all-powerful, all-knowing person out there who knows what’s best for you. You do (Young, 2002).

Unfortunately, as Internet accessibility and usage increase, Americans also face a decline in the amount of time physicians are physically able to spend with their patients. As the U.S. population grows and the percentage of elderly Americans rise, physicians are finding it
increasingly difficult to spend the amount of time necessary to properly and effectively address all of their patients’ medical questions and concerns (Wilkins, 1999). R. Cline and K. Haynes argue in “Consumer health information seeking on the Internet: the state of the art”:

67% of physicians report having patients who discuss with them information received from the Internet…Consumers [or patients] may confront providers who are unprepared to deal with the magnitude of available information (Coiera, 1996) [sic], with patients sometimes having greater information access than their providers (Cline & Haynes, 2001, pp. 5).

As such, there is “an opportunity for partnerships in healthcare…and a greater use of the consumer as a resource” (Cline & Haynes, 2001, pp. 5). The Internet has and will continue to become a crucial component of health literacy, patient education, and condition management. Therefore, it is important that we understand the ways in which online health resources influence patient treatment decisions. More importantly, however, it is vital that we understand how these decisions affect the condition or disease itself.

According to a 2010 Pew Internet & American Life Study, “Chronic Disease & the Internet,” 51% of those Americans living with one or more chronic illnesses(s) engage in online health-searching behaviors (Fox & Purcell, 2010). As compared to the online health behaviors of those living without a chronic illness, patients with a chronic illness are more likely to search for specific condition-based information, treatment options (both traditional and experimental), and patient-generated online information (Fox & Purcell, 2010).

For instance, in a study of women diagnosed with breast cancer, Kroenke et al. found women who did not have a strong social network or support system had an increased risk of mortality: with a 66% “increased risk of all-cause mortality” compared to those women with a strong
support group (Kroenke et al, 2006, pp. 1105). In the area of HIV/AIDS, Patricia Reeves asserts that “Internet use fosters adaptive coping efforts and offers yet another strategy for individuals in their struggle to live with HIV” (Reeves, 2000, pp.57). Therefore, coping strategies, together with a strong support group helps in facilitating a stronger sense of emotional wellbeing, which in turn, can impact one’s physical health.

4.2. The Empowered ePatient? The Internet as a Tool for Boundary-Breaking

As argued by Marie R. Haug and Bebe Lavin in their work, “Practitioner or Patient – Who’s in Charge?”, our current society has seen a reversal in the *sick-role model*. A new model “based on consumerism and authority challenges rather than authority acceptance” has emerged between the physician and patient (Haug & Lavin, 1981, pp. 213). This tendency to bargain and negotiate is very similar to the tendencies of the post-modern “consumer” patient. Many within the medical community regard the emergence of the self-empowered and self-educated patient as a disturbance (and a hindrance) to proper and effective medical care. However, everyone involved in the practice of medicine (the medical community and the public alike) must accept the fact that medical knowledge and information is out there and it is easily accessible. The patient and the physician are both equipped with a certain type of medical knowledge and opinions that will inevitably impact health-related decisions (for better or for worse).

Kristin K. Barker refers to this increased patient-driven consumerism as *patient-generated medicalization* (Barker, 2008, pp.23,31). In her work, “Electronic Support Groups, Patient-Consumers, and Medicalization: The Case of Contested Illness,” Barker examines the effects of an electronic support group (ESG) on Fibromyalgia sufferers. In the case of Fibromyalgia, many Fibromyalgia patients live a life untreated—experiencing chronic pain that the majority of
physicians believe to be symptoms of depression. As Barker illustrates, patients with conditions like Fibromyalgia band together in an effort to secure physician-compliance. Patients enact physician-compliance by demanding that medical professionals “accept [their] patient expertise...[and acknowledge, respect, and adhere to] a patients’ embodied knowledge” (Barker, 2008, pp. 23, 31).

This behavior is further perpetuated by the availability of technology and resources, such as diagnostic and symptom-based tools. These resources, which once encouraged a centralization of medicine in the clinic or hospital (a single place), are now available online (in multiple places and in a variety of forms). For instance, WebMD.com helps visitors to assess whether or not they are experiencing symptoms of various conditions by simply filling out an electronic diagnostic screener. Patients can also facilitate the process of diagnosis and treatment by referring to the advice of patients in similar situations. Members of patient-generated data websites, as with PatientsLikeMe.com (PLM), can now compare the efficacy rates of various medications (and dosages) among patients in similar situations. With access to self-reported medical records, PLM members can view the medical information of other members in order to make an informed decision regarding their own treatment plan.

In some cases, patients gain insights that many times their physicians were unaware of. For instance, Thomas Goetz of The New York Times describes one such case. Todd Small, suffering from Multiple Sclerosis (MS), grew frustrated by the continuous stiffening of his muscles while walking (a common MS symptom). After, joining the MS community on PLM, Todd discovered that the medication he had been taking to treat his stiffness would be more effective at a higher dose. As Goetz describes:
Contrary to what his neurologist told him years ago, 10 milligrams [of this particular drug] wasn’t the maximum dose. In fact, it was at the low end of the scale. ‘They’re taking 30, 60, sometimes 80 milligrams—and they’re just fine’…A few days later, Small asked his neurologist to up his dosage. Now Small takes 40 milligrams of baclofen a day. His foot drop isn’t cured…but he has found that after 14 years, he can walk to his car without [feeling like he is] sinking in quicksand (Goetz, 2008).

Patients are increasingly utilizing tools that allow them to actively participate in the practice of medicine. With the amount of information online, patients can often misdiagnose themselves, and in some extreme cases, self-medicate in ways that prove to be quite dire. Nonetheless, strides have been made when walls between medicine and the public crack. In the case of Todd Small, for instance, a change in medication dosage made all the difference.

Our convergence culture has decentralized the control and the power of exclusive knowledge production. The ability for medical information to act as a boundary-object (Star & Griesemer, 1989), or a tool facilitating the division between the expert and the layperson, is gradually dissipating. Currently, most Americans have the ability to acquire the same amount (not necessarily type) of knowledge as any traditional expert. More importantly, a large majority of the public has the ability to produce and create knowledge that can be considered (by some) to be just as or even more credible and trustworthy than the knowledge produced by the medical professionals. Similar to the times of bedside medicine, to some extent, place is beginning to return back to the patient’s turf. Patients now have the ability to take “advantage of their computers to find health material in this ever-expanding body of knowledge” (Hardey, 1999, pp. 830).
As Dr. Paul Wicks, Research & Development Director of PLM, describes there are clear differences between the “old paradigm of medicine…the old guys [who] are dying…[and] retiring,” versus “the next generation” of physicians and researchers, who “grew up in a time of the web as something that was part of their lives. They’re getting promoted, they’re now the attendees, they’re now the profession” (Wicks qtd. in, Polk, 2010, pp.18). According to Dr. Wicks, a new “meme” is surfacing, where a younger generation of physicians and clinical researchers are beginning to “realize that in certain fields of research, patients can contribute more than the old guys used to think they could” (Wicks qtd. in, Polk, 2010). This, in turn, raises the question of: Who is in charge: The patient or the ‘younger generation of physicians and clinical researchers’?

5.0. From Theory to Practice: Diving into the Data

This chapter places a great amount of emphasis on the context of the physician-patient and researcher-participant relationship—contextualizing shifts in boundaries, as they relate to place, technique and technology. Nonetheless, it is important to examine specific behaviors of technology use and trace the activities of certain actors involved in instances of boundary-breaking. As evidenced in the preceding pages, large amounts of research investigate lay (patient) expertise, and its impact on both the physician-patient encounter, as well as the clinical study/trial setting. Literature also exists on the ways in which patient online health-information seeking and ePatient expertise impact the traditional medical encounter (namely, the doctor’s office visit) and the blurring of boundaries.
By introducing boundary-breaking, I tie the literature together by bringing in an over-arching phenomenon—consisting of progressive and nuanced shifts in place, techniques and technology use. Boundary-breaking bridges the old techniques of lay incursions (Epstein, 1995) with the new proliferation of patient technology use occurring online.

I apply boundary-breaking to two specific case studies. The first case study (Chapter III), highlights the Heywood family and their efforts to save one of their family members diagnosed with the terminal disease ALS or Lou Gehrig’s disease. Specifically, I examine the journey the Heywood’s take in developing their own research foundation (the ALS Therapy Development Foundation or ALS TDF), in the hopes of finding a cure for ALS faster than the medical community itself. The second case study examines the Heywood’s next venture: the online patient data-sharing platform, www.PatientsLikeMe.com or PLM. In the context of PLM, boundary-breaking occurs among a variety of actors, including the patients willing to put their medical information online and the PLM employees decisions as to who to sell the patient data to (i.e. pharmaceutical companies, government and academia).

Upon analyzing these two specific case studies, sites and set of actors, the chapters that follow illustrate that the strategies and behaviors behind boundary-breaking are complex and vary over time. That is, in some cases, elements of boundary-making can in fact emerge before, during and even after boundary-breaking efforts. While the initial goal of breaking down boundaries can be that of collaboration and collective knowledge sharing between experts and lay patients, members of these movements (whether medical professionals or the patient community itself) can (intentionally and unintentionally) become new experts and another layer of power. With good intention and patient empowerment in mind, some new age researchers can adopt “an
ideological style...[in an] attemp[t] to create a public image for science [or a specific cause or type of expertise] by contrasting it favorably to non-scientific intellectual or technical activities [or the expertise of their opponents]” (Gieryn, 1983, pp.781).
CHAPTER III
A CASE OF BOUNDARY-BREAKING (PART I): FINDING A CURE FOR AN ORPHAN

1.0. Introductory Comments: Boundary-Breaking In Action

In an effort to understand boundary-breaking this chapter examines the actions of a specific set of lay actors. Specifically, I examine boundary-breaking by tracking the Heywood family, as they set out to find a cure for one of their family members (Stephen Heywood) suffering from the incurable disease, Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig’s disease. By following the behaviors, relationships and techniques employed by the Heywood’s over the course of their journey, this chapter unpacks each element of boundary-breaking as they emerge in situ. Boundary-breaking takes on many forms, creating a sequences of actions. As such, before this concept can be universally applied or even accepted, I examine it first in a case where it clearly exists. Broken into two specific phases of analysis (Chapters III and IV), the Heywood case study is examined. First, in this chapter, I analyze the Heywood’s creation of an ALS research foundation in 1999: the ALS Research Foundation (ALS TDF). In Chapter IV, I move my analysis to the Heywood’s next creation: the 2005 launch of the patient-generated data-gathering website, PatientsLikeMe.com (PLM).

The Heywood’s boundary-breaking efforts include the use of specific places, technologies, and techniques that allow for them to understand, participate, and most importantly, change the practices and structure of medical research. In doing this, the Heywood brothers—Jamie, Ben, and Stephen—work to acquire the knowledge, skills, and credibility of those experts within the walls of the ALS medical community. In particular, Jamie, exhibited a strong determination to engage in medical knowledge production. Boundary-breaking, in this case, consists of
relationships (defined in stages) between patients, activists, experts and the institutions associated with ALS research. In this context, I argue boundary-breaking occurs in three specific stages: 1) The Personal Fight, or the initial actions taken by the Heywood family upon receiving Stephen Heywood’s ALS diagnosis; 2) Accruing a Team, or the strategies employed by the Heywood family and friends to involve and convince outside individuals (both medical professionals and patients) to join the personal fight and cause; and lastly, 3) Marketing a Mission, or the slow transition from a personal fight to a larger foundational goal of changing the practices of a large organization, and in this case, how medicine conducts research (as with the development of the ALS Therapy Development Foundation). In this case study, each of the three categories or stages above build upon and progressively initiate the next sequence of actions: that is, in this case, the personal fight paved way for the creation of a team (and foundation), which in turn, facilitated interactions with larger institutions and medical professionals. However, as I will show the process is dynamic—for instance, the personal fight can reemerge in times of stress or contrasting opinions within the larger team or foundation.

Much like Millerand et al.’s arguments in “Making an Issue out of a Standard: Storytelling Practices in a Scientific Community”, many of the Heywood’s include:

[E]fforts and activities of [Jamie, Ben and Stephen Heywood], who in seeking to understand private troubles [the personal struggle and determination to save a family member], transformed the troubles into institutional issues [issues that matter to the larger medical and patient communities, i.e. there is no cure for ALS, orphan disease should be acknowledged, and medical research needs to be conducted more efficiently] (Millerand et. al, 2010, pp.25).
As the actors are followed over time, shifts in place, and thus, the techniques, and technologies used to engage the large medical system become clear—with each shift, troubles are transformed into issues.

1.1. Setting the Stage: Introducing the Case & Its Actors

Diagnosed with ALS in December 1998 at 28-years old, Stephen’s prognosis, like many other ALS patients, gave him an approximate life span of two to five years. Referred to as an orphan disease, ALS is one of the many conditions where the number of sufferers does not generate enough revenue for industry and institutions of research to pursue. Unfortunately, there is no cure for ALS. Currently, there is only one treatment available for ALS: Rilutek, which simply acts as a short life-extension (months). While Stephen’s initial reaction to his prognosis was to “‘go buy that Harley [he had] been thinking about,’” his older brother, Jamie, reacted quite differently (Jamie Heywood, qtd. in Ascher & Jordan, 2006). On the very day of Stephen’s diagnosis Jamie decided and became determined to find a cure to save Stephen. Similar to the AIDS treatment activists of the 1980s and 90s (Epstein, 1996), Jamie, a trained engineer and employee of the Neurosciences Institute, dove into the ALS data. He immediately began to familiarize himself with the medical research—learning the terminology, and reaching out to those within the ALS expert community to find answers. Jamie wanted to know what the experts knew. But, in this initial step towards boundary-breaking he, like the AIDS treatment activists (Epstein, 1996), had to learn about ALS on the expert’s terms (i.e. their terminology and their literature).

The ALS Therapy Development Foundation or ALS TDF, co-founded by Jamie and the Heywood family (including Stephen Heywood himself) started its efforts in 1999. Jamie, along
with his family and childhood friend, Robert Bonazoli, started ALS TDF in an effort to speed up the process of drug trials and ALS treatment discovery. The initial mission: Save Stephen’s life. As the foundation grew, the foundation’s place shifted from the Heywood’s basement to an official office in their hometown of Newton, Massachusetts. This office included a bona fide laboratory, where they planned on creating one of the largest mice labs devoted to ALS research.

To run this lab, the foundation needed professionals skilled and trained in this area of research. Many scientists and even patients flocked to join the Heywood’s (and ALS TDF) to conduct what many referred to as “guerilla science” or “high-risk/high-reward” research (Weiner, 2000; ALS TDF, 2000). As the foundation established itself both within the patient community, and slowly, within several medical circles, the personal fight transitioned into a larger medical mission. As such, this mission needed to be marketed and sold universally in order to effectively enroll as many individuals with 1) the technical skills, 2) expertise, 3) drug supply and 4) financial resources to find a cure as fast as possible.

2.0. The Personal Fight: The Effects of an ALS Diagnosis

In the case of the Heywood’s, the personal fight began with Stephen Heywood’s diagnosis in 1998. The Heywood’s personal fight consisted of instances where the “fam[il]y [attempted to] direct research themselves because they [were and] are impatient with the bradykinetic pace of conventional science” (Rowland, 2012). The Heywood’s:

[B]egan clamoring for the rapid approval of experimental treatments…[claiming as] John James, a former computer programmer and the editor of AIDS Treatment News, had [in] sound[ing] a call to arms…To ‘rely solely on official institutions for our information…is a form of group suicide’ (Epstein, 1995, pp. 416).
At the time, AIDS was considered a death sentence. By contrast, ALS has and continues to be just that. In order to find a cure for Stephen, the personal fight needed to include individuals outside of the family. Namely, individuals who had access to the materials, skills and network that would allow for the research to take place. Before the Heywood’s could engage the system, they first needed “a dream team” (Weiner, 2004, pp.143).

In describing his brother, Stephen Heywood states in an interview with CBS’ 60 Minutes: “[Jamie] sees my deterioration as a personal affront, as a personal reminder of how slowly he thinks he’s going” (Stephen Heywood, qtd. in CBS, 2000). Jamie did not have the time or luxury to sugarcoat his goal. His brother had approximately two to five years to live. Finding a cure, in the case of the Heywood family, was personal and the lack of expert attention to this cause became a fight against the disease and the medical community.

Science writer and journalist, Jonathan Weiner, first described Jamie Heywood as a guerrilla scientist in a February 2000 New Yorker Magazine article entitled “Curing the Incurable.” The term “guerrilla” representing Jamie and his family’s unyielding determination to do whatever it took to save Stephen. Labeling the Heywood’s as guerrillas is worth unpacking. While, at first, the term seems a bit aggressive, the journey the Heywood family initially took to find a cure for Stephen follows guerilla-like techniques. When something is personal, underscored with the fact that nothing is being done to help a particular loved one or friend, Jamie adopted (in the view of the medical and science community) a fight mentality. For example, in a discussion captured in Steven Ascher and Jeanne Jordan’s 2006 documentary film on the Heywood’s, So Much-So Fast, Jamie speaks with one of the leading ALS researchers, Dr. Jeff Rothstein, at the Society of Neurosciences’ Annual Meeting, about the goal of ALS TDF (the foundation):
Jeff Rothstein: “So, have you passed this by someone who designs trials? It’s not peer reviewed. So, how do you know how you delivered it? What the dosing is? How long you did it?”

Ramesh Tennore [a molecular biologist and one of the members of ALS TDF]: “We have all the information here [he points to the webpage where all the foundation’s trial information was housed]. Public access.”

Rothstein: “That’s great, but that is not how we live” (emphasis added).

Jamie: “But, you don’t question the rules you operate in. What makes you think that this…”

Rothstein: “Oh, that’s so naïve.”

Jamie: “It’s not naïve. Don’t Jeff. You are like the consulate academic…You are like ‘Do you know how to play the game?’ We are questioning the whole infrastructure that sets up the whole thing.”

Rothstein: “You want to be the anarchist you can…”

Rothstein: “If you just took away some of the rhetoric about ‘you guys don’t know what you are doing.”

The conversation between Jamie and Rothstein is full of us versus them sentiment. Jamie is, in a sense, justifying his knowledge of the field, which for him bolsters his personal fight. By paying particular attention to the bolded phrases of “not how we live”, “rules you operate in” and “we are questioning the whole infrastructure” the separation between the lay and the expert is pronounced. At the same time, however, the conversation illustrates initial steps in engaging the medical community. That is, while Jamie hopes to engage Dr. Rothstein (in order to enroll him in his cause), this instance of boundary-breaking also involves components of boundary-making. Jamie “question[s] the whole infrastructure” the medical experts work within; while, Rothstein separates himself from Jamie by using labels such as “anarchist” and directly acknowledges controversial “rhetoric” he feels Jamie and his cause engages in (Ascher & Jordan, 2006).
Similar to Thomas F. Gieryn’s boundary-work, certain discourses (or rhetoric) are used by both Jamie and Rothstein, as a means of demarcating real science from flawed or non-science.

It is also important to acknowledge Dr. Tennore’s reference to “public access” in the dialogue between Jamie and Rothstein, as this represents another set of techniques and technology used by ALS TDF to make their personal fight known. In order to find a cure, the foundation believed that not only should the “whole infrastructure that sets up” medical research be questioned, but everyone should have access to the medical information the foundation produces. As Jeff Cole, co-founder of PatientsLikeMe.com, and a personal friend of the Heywood’s and former member of ALS TDF, describes the foundation’s public access:

Essentially, it was publishing which studies were in which phases in their [the foundation’s] pipeline cause they did all mouse studies over there…. [T]hey actually had a whole process for the funnel of here’s all the possible leads we could follow-up on, here’s the first pass research we do on them, here’s the one that actually go into mouse studies, and here’s the results of the mouse studies. So, to some extent it was sort of taking that pipeline and making that visible to everybody…It wasn’t actually showing masses of data or anything. I don’t know if anyone would know what to with it at all (Cole, qtd. in Polk [interview], 2010, pp.32).

Via an online platform, ALS TDF put any and all of its findings on the Internet in order to give everyone (both patients and experts alike) an opportunity to engage in and contribute to medical knowledge production. Clearly, this technique broke some of the traditional boundaries, as evident in Rothstein’s remark: “That’s great, but that is not how we live” (Rothstein qtd. in, Ascher & Jordan, 2006).

At this stage in the Heywood’s journey, the Heywood brothers, and particularly, Jamie, had to use the terminology and more importantly, the medical knowledge produced by the ALS
experts—their ability to find a cure still required them to first learn, understand and see the disease as the experts do (not necessarily on the Heywood’s own terms).

For example, when Jamie first found out about his brother’s diagnosis, he explains that his initial reaction was to understand the information that was already out there concerning ALS: “I dove in and built this book. I just started printing things and organizing them. What was this, what does this mean? Every trial, everything that was going on and there are hundreds of good ideas that we just don’t pursue” (Jamie, qtd. in, Asher & Jordan, 2006). This book consisted of a three ring binder filled with medical articles and clinical studies—all of which include language and terminology that Jamie had to teach himself, with the help of friends he had within the ‘expert’ community.

Furthermore, as one neuroscientist describes, “I assumed right up front that he was a biologist...He was so familiar with the research basis, that it wasn’t until I actually met him that I realized he wasn’t—he didn’t have a biology background” (Ascher & Jordan, 2006). Similarly, in an interview with PBS’s “FRONTLINE,” Wendy Heywood, Stephen Heywood’s wife, describes how she educated herself about ALS:

Our [the family’s] medical databases were the ones in Jamie and Stephen’s heads! Jamie was amazing in his drive to research the equipment, medications and medical interventions Stephen would need throughout each step of his progression. Stephen spent much time on the computer researching other patients’ stories and comparing all types of equipment he would need to meet his needs. We were always one step ahead because of this (Wendy Heywood, qtd. in, FRONTLINE).
As evidenced in the behaviors and strategies initially employed by the Heywood’s, the personal fight, (which lies between boundary making and boundary-breaking), follows similar patters to those used by the AIDS activists of the 1980s.

Like the AIDS activists, the Heywood’s personal fight first involved small “lay incursions into biomedicine,” where Jamie and Stephen had to extensively study and engage in self-training in the area of ALS and medical research (Epstein, 1995, pp.409-10). It was this self-education that lead to the description given earlier: some experts in the ALS community “assumed right up front that [Jamie] was a biologist,” due to knowledge of “the research basis”’’ (Ascher & Jordan, 2006). Thus, similar to the AIDS activists, Jamie acquired knowledge, which allows him to discuss topics and engage in discourse that was typically discussed and employed only by and within the medical ALS community itself. Yet, boundary-breaking at this stage still resides on the experts turf—Jamie had to understand them, before his true fight could really lead to something substantial.

The Heywood’s had to go to the where the experts were: one such place being the Society of Neurosciences’ Annual Meeting. As documented in So Much-So Fast, ALS TDF’s first visit to this meeting occurred in 2000. Steve Ascher describes his reaction to how the society members (comprised primarily of scientists) perceived Jamie: “I could see how controversial Jamie was. To a lot of scientists, it seemed like he was claiming that he, a non-scientist, was going to figure something out faster than anyone in the field” (Ascher, qtd. in Ascher & Jordan, 2006). Jamie’s reputation among these professionals is that he, a non-expert, believes himself to be better equipped to accomplish what the experts have spent years of training and research to do.
The truth is, Rothstein’s reference to the rhetorical techniques Jamie and his team used can be found directly in the ALS TDF’s first “Annual Report” generated in 2000. With the tagline “Challenging the Boundaries,” the report makes the following clear:

By contrast to “[a]cademic centers [which] are not set up to complete repetitive and comprehensive tasks, and biotechnology companies [which] pursue projects that will develop profit,” ALS TDF “marks its success by gauging the degree to which ALS patient’s needs are met…the profit potential is not measured in dollars, but in lives” (ALS Therapy Development Foundation, 2000, pp.12).

In calling attention to the weaknesses of the academics and drug companies, the foundation not only creates an antagonistic dialogue between experts and the lay, but reinforces Rothstein’s above concern regarding “the rhetoric about ‘you [the ‘experts’] don’t know what you are doing” (Rothstein, qtd. in Ascher & Jordan, 2006). Interestingly enough, as we will see later on in this chapter, over time and as the foundation progresses and matures, so too does the language within the annual reports—the guerrilla is tempered and alignment with and within the larger medical system emerges.

Jamie’s personal fight is directly described in an interview with Steve Ascher in So Much-So Fast. In describing the departure of one of the foundation’s key members, Robert Bonazoli (a long-time family friend of the Heywood brothers) the following conversation ensues (Ascher & Jordan, 2006):

**Steve Ascher**: “So, big changes at the foundation?”

[Jamie whistling as he sits in the interview chair]

**Jamie**: “Cue the layoffs” [with a smirk]. “Cue the layoffs” [more serious this time].

**Ascher**: “Robert’s leaving.”
Jamie: “Robert gave more than anyone would ever reasonably expect anyone to ever give to the effort. I mean it wasn’t his battle. It wasn’t his fight… He genuinely does believe that if you treat people well and do it the right way, you know you will be… He is just genuine and yet I don’t see in him ambition” (emphasis added).

Ascher: “He joined up with you to do this thing. What did you…”

Jamie: “What thing? You know, I mean it changes over time. I mean the thing was trying to save Steve, um…”

Ascher: “Well, you don’t think that is what he wanted to do?”

Jamie: “Then he was a pretty naïve man to sign on, the odds are pretty slim.”

Ascher: “He said that he believed in the power of a group of people setting off on a mission and whether you go to the end or not wasn’t the main thing.”

Jamie: “Maybe that’s the tension. I just want to get to the end. I mean that’s actually it. Maybe it isn’t the journey to me” (emphasis added).

In the above conversation, the personal fight resonates throughout. Jamie is determined to “get to the end”— this “end” not being a “journey” but a “battle” and “fight.” The personal fight, consisting of what the actors in this case, refer to as guerrilla scientists, first react to a tragedy, such as a family member or a loved one’s fatal diagnosis, as personal and an “affront.” Nevertheless, in order to find a treatment, those who have access to particularly resources and knowledge are needed—the breaking down of us versus them emerges when experts are invited into the mix.

3.0. Accruing the Team: Letting Outsiders In

In accruing a team, the foundation needed to target specific medical professionals willing to work “on the edge of medicine” to find a cure—a group of “mavericks” prepared to defy the protocols of traditional medical science by “going directly for the drug without working out the
details of [a medical] theory” (Weiner, 2004; Ascher qtd. in, Ascher & Jordan, 2006). In the case of the Heywood family, the creation of a small foundation (referenced in earlier section), ALS TDF, caught the media’s attention—the foundation’s “reputation as guerilla scientists was bringing in patients around the country and scientists wanted to join up” (Ascher & Jordan, 2006). When accruing a team, the Heywood’s looked specifically for what I define as three specific types of mavericks: 1) the ‘Personal-Amateur’, 2) the ‘Personal-Professional’, and 3) the ‘Professional’. Each maverick type motivated, and thus, contributing a certain and specific form of knowledge and set of skills, to the collective community and overall mission.

When Stephen was first diagnosed with ALS, Jamie was an employee of the Neurosciences Institute—hired to bring both his engineering and entrepreneurial skills to the small research company of scientists. This put Jamie in a particularly beneficial position—he was able to use the Institute’s name as a foundation of credibility when reaching out to experts in the field of ALS. The ALS TDF foundation started in the basement of the Heywood’s home: “Just Jamie, his wife Melinda, [and] Stephen’s high school friend Robert Bonazoli” (Ascher & Jordan, 2006). However, before one can engage the system, one must first create “a dream team” (Weiner, 2004, pp.143).

This team generally consists of specific professionals, ‘mavericks’ willing to work and “invest in this unique, high-risk/high-level venture called ALS Therapy Development Foundation” (ALS Therapy Foundation, 2000, pp.12). Many scientists were intrigued by the foundation’s mission and in particular the media attention Jamie and his brother’s were receiving with regards to their foundation: ALS TDF’s “reputation as guerilla scientists was bringing in patients around the country and scientists wanted to join up” (Ascher, qtd. in, Ascher & Jordan, 2006). But, why did
“scientists wan[t] to join up”? In unpacking the notion of ‘mavericks,’ motivations become clearer and the next step in boundary-breaking emerges.

As described in the introduction, mavericks come in three specific types: 1) the ‘Personal-Amateur’, 2) the ‘Personal-Professional’, and 3) the ‘Professional.’ Each maverick motivated, and thus, contributing a certain and specific form of knowledge and set of skills, to the collective community and overall mission. The personal-amateur maverick includes individuals like Jamie, his brothers and the family at large—non-experts (guerrillas in a sense) motivated to accomplish a specific set of goals. The personal-professional maverick is one who has both a personal and professional interest in the cause—that is, this individual has a personal connection to a specific disease, such as ALS (i.e. a family member suffers from the disease), in addition to a professional background, and in this case, a medical professional (i.e. a scientist, a biologist, or a clinician). The professional maverick is one already in and/or associated with the medical system—intrigued and/or interested in helping and contributing to this novel and “high-risk/high-level” adventure (ALS Therapy Foundation, 2000, pp.12).

The mixture of these three types of mavericks becomes crucial as the foundation’s cause progresses, with each type establishing credibility and ultimately, collaboration, between and among expert (medical professional) and lay (patient/ caregiver) communities. Upon introducing and analyzing each maverick type, a common thread that binds each type together emerges. This thread being a mutual appreciation and desire to change the medical system at large—“‘a whole new kind of medicine…A new way’” of conducting medical research (Jamie, qtd in. Weiner, pp.233).
Similar to his guerrilla status, Jamie also represents a prime example of the personal-amateur maverick: his personal motivation being to save his brother Stephen’s life and his amateur status being that of his non-science background. Nevertheless, Jamie’s skills in engineering, salesmanship, and his unwavering drive, proved to benefit the foundation’s impact greatly. That is, the personal-amateur is essential to the foundation—providing a certain set of skills and knowledge the mere professional maverick cannot necessarily provide. As one of the foundation’s scientists described him, Jamie “sort of has an eggshell thin knowledge of what we’re doing, at least on the science side and all. His ability to sell what he’s doing with it is incredible—that’s what I think his talent is” (Baker, qtd. in., Asher & Jordan, 2006). Correspondingly, Matt During, a neuroscientist associated with the foundation, described Jamie as “know[ing]” his stuff. Jamie knew the lingo. Jamie knew enough biology, knew enough science, knew enough at every level of this project to be able to make an impact. You need both money and energy and insight in terms of biology and (to) be able to put people together” (During, qtd. in CBS, 2000). This “energy” and “selling” talent is crucial in exciting the other types of mavericks.

His selling talent is illustrated in a conversation Jamie and two ‘expert’ members of the foundation have with a representative from Mayo Clinic:

**Jamie:** “I don’t know if Remesh [a biologist on the team] told you, but the foundation was formed because my brother has ALS, which is why we came into existence…I would prefer that clinicians experimented with their patients” (emphasis added).

**Mayo Clinic:** “For sure, you are going to have patients that are going to die.”

**Jamie:** “Someone challenged my recommendation of a drug to somebody. I may not be an MD, but there are four PhDs here that are researching the potential side-effects and interactions of this drug [one of the many potential and promising treatments the foundation
had found] in correlation to every other drug using every pharmacology reference that exists in the world” (emphasis added, Jamie, qtd in Ascher & Jordan, 2006).

Jamie’s direct comment asking “clinicians [to] experimen[t] with their patients” showcases his personal connection and drive to find a cure. Jamie did not have the time or luxury to sugarcoat his goal—his brother had approximately two to five years to live. Furthermore, his reference to the “four PhDs” allows Jamie to break the boundary down between his amateur status and the Mayo Clinic representative’s expert position.

In reference to the PhDs mentioned above, the personal-professional maverick is introduced. One of the PhDs Jamie refers to on the phone with Mayo Clinic is Ramesh Tennore, a trained molecular biologist. He joined the foundation not only to apply his knowledge and skills, but more importantly, “to help his sister-in-law, who has ALS” (Ascher qtd. in, Ascher & Jordan, 2006). Dr. Tennore is profiled in ALS TDF’s 2001 Annual Report. In describing his motivations for joining the foundation, the copy below Dr. Tennore’s picture states:

Dr. Tennore quit his job as a research scientist for biotechnology company CuraGen, determined to help [his sister-in-law, Canan]. The Foundation’s focus on finding effective treatment’s for today’s patients, along with its commitment to scientific rigor and its open-minded approach to curing ALS, convinced Dr. Tennore this was the place he could fight to make a difference for Canan and patients like her (ALS Therapy Development Foundation, 2001, pp.6).

Thus, as an example of the personal-professional maverick, Dr. Tennore possesses both the drive of Jamie (a personal fight), in addition to a professional background that helps him scientifically “fight to make a difference.” In addition to Dr. Tennore, one of the foundation’s chemists, Larry Manes, joined the foundation. However, unlike Jamie and Dr. Tennore, he has an even greater
stake in the matter: he himself suffers from ALS. While Manes, recognizes that the foundation is “outside of the norm...proposing ideas that can very easily be shot down” by what Manes refers to as “the establishment,” he argues that “[f]rom a scientific standpoint, [he] believes that we [the foundation] can find some very effective things” (Manes qtd. in, Ascher & Jordan, 2006). The combination of the personal and professional adds another insight into the cause—their status or titles within the medical system can be leveraged, while at the same time, their personal motivations provide them an opportunity to exploit their very position within medicine.

The professional maverick is different from the two other types of ‘mavericks’ described above. Their ‘personal’ commitment to the cause is not as clear—that is, there is no direct, or rather, obvious, personal connection to the disease, and in this case, ALS. With regards to those professionals attached to the foundation, Dr. Matt During represents the best case. Neuroscientist, Matt During, was one of the initial experts Jamie reached out to—his work in gene therapy (which Jamie read extensively) intrigued Jamie.

As Weiner describes: “Matt had been called a maverick for his [previous scientific] work. ‘I have a reputation as something of a cowboy’...[During had stated. And] Jamie was pushing the cowboy” out of During (Weiner, 2004, pp.245). Nevertheless, his professional stance and expertise provided the foundation and namely, those with personal stakes in the matter, a sense of reality—it especially brought Jamie down from the clouds. For instance, when describing Jamie During states the following in So Much-So Fast:

You know, the trouble is, you can touch at all these straws and go nowhere. So, you need some sort of structure to it [the foundation and its research], some overall master plan. Not just chasing after everything. And I think one of the dangers, one of the few dangers that I
guess of Jamie is that he gets maybe a little too buoyant, too excited about something that he’s just heard about (During, qtd. in, Asher & Jordan, 2006).

Jamie wanted to try everything: “I have a hundred drugs with good rationale, how do I pick? I have a brother who has maybe three years to live and I need to get an answer to that. And what’s amazing is how much that cuts through every piece of bullshit” (Jamie qtd. in, Ascher & Jordan, 2006). In this sense, the professional maverick was willing to try things the system was not necessarily trying, but in a way that would not tamper or ravish the foundation (and its members’) reputation and more importantly, credibility. This sense of realism transitions nicely into the next section, discussing the ways in which the foundation attracted attention, funders and membership. In order to establish a new way of conducting medical research, the knowledge of all three sets of mavericks needs to be leveraged. To successfully persuade the medical system at large one needs to convince them that the foundation’s work is trustworthy, solid, and worthy of attention/respect. Similarly, the foundation also needs to convince patients and caregivers that the mission was not, in a sense, a form of “false hope” (Ascher qtd. in, Ascher & Jordan, 2006).

4.0. Marketing a Mission: From the Personal Fight to a Greater Cause

When searching for a cure (for a disease deemed incurable), it takes more than a group of thirty to forty mavericks to provide the resources necessary to fund the research, discovery, treatment and ultimate, drug supply—to accrue a team is one thing, but to enroll medicine is another. Given ALS’ its orphan status, the group of amateurs and professionals within ALS TDF had to catch the attention (credible attention, that is) of those who have the power to help initiate and feed the mission—attention that requires a transition from a personal fight to that of a
mission which must be marketed—or as Jamie Heywood refers to it—ALS TDF needed to show ‘WIFF’M’ or “What’s In It For Me” (Weiner, 2004, pp.80)? That is, one must “[s]how the other guy [the experts or patients] what’s in it for him and he will buy your idea every time” (Weiner, 2004, pp.80). As it relates to finding a cure for ALS and the foundation’s goal, the personal fight (to save one individual) transforms to a marketable mission that includes universal appeal both on a personal and professional level.

According to Weiner in *His Brother’s Keeper: A Story From The Edge of Medicine*:

Now and then, as a favor, [Jamie] designed his new friends [co-workers at the Neurosciences Institute] a piece of lab apparatus, or coached them in the principles of business plans, dot-com entrepreneurship, and salesmanship. It’s got to have WIIF’M, Jamie said. That was one of his favorite acronyms: WIIF’M, What’s In It For Me. Show the other guy what’s in it for him and he will buy your idea every time. Almost every day he stopped by Ralph Greenspan’s office [the founder of the Neurosciences Institute]. I’m going to make you a rich man! Jamie liked to say. I’m going to make you all rich” (Weiner, 2004, pp.80)! It is this exact acronym, *WIFF’M*, which plays a crucial role in enrolling, or rather, engaging the medical system at large—to continue to chip down the boundaries between the lay and the expert (or rather the outsiders and the insiders), ALS TDF needed to slowly move away from solely the personal to that of the larger ALS community. That is, one must “[s]how the other guy [the experts or patients] what’s in it for him and he will buy your idea every time” (Weiner, 2004, pp.80). As it relates to finding a cure for ALS and the foundation’s mission, two central elements drive the effectiveness of demonstrating the WIFF’M: the personal motivations (primarily targeted at the emotional strings of the disease) and the professional allure (focusing on the novel
and potentially changes a potential member could gain from aligning oneself with the foundation).

The personal motivations focus on the patient itself and the current state of the disease (namely, the treatment options, or lack thereof, for a disease like ALS). The notion of ‘now’ emerges throughout the testimonials of ALS sufferers and loved one’s—with an incurable disease, such as ALS, and a life span of approximately, 2 to 5 years, there is no time to wait for a cure, time is not on an ALS patient’s side. In Jamie and Stephen’s 2000 interview with CBS’s Charlie Rose of 60 Minutes the following occurs, when Jamie is asked about his reaction to his brother’s diagnosis:

No one was developing anything that was going to arrest the disease, says Jamie Heywood incredulously. There was no one saying, ‘This is something that’s going to stop this disease [ALS] from killing people’…‘There’s all these great ideas sitting in these laboratories waiting for someone like us to come in…Every doctor I’ve spoken to from the beginning has said to me, when we talk about these trials, we have to be careful…We first do no harm. Well, in this case harm is being done every single day. And if we delay something a year, then we’ve just done a great deal of harm (emphasis added, CBS News, 2000).

Jamie’s reference to “harm” is quite interesting: medical professionals see ‘harm’ in one way, while loved one’s and those suffering from ALS see harm in quite another. As Jamie directly states, when it comes to ALS one does not have time “to be careful”: For Jamie, being careful means a potential loss of life, these patients, and particularly, his brother have nothing to lose. It is this sense of urgency that not only motivates the patient and caregiver to say something, but also has the potential to entice the larger system.
Similar to the notion of now, (in the temporal sense), ‘today’s patient’ comes into play (both in a behavioral sense, as well as a temporal sense). For instance, today’s patient is no longer passive—patients, and in this case, ALS sufferers and their family members/loved ones, demand, and at times, initiate a change:

From the beginning, the foundation…brashly set out to break the protocols of the drug discovery process and change the paradigm for ‘disease nonprofits.’ Rather than fundraising, the organization, then known as ALS Therapy Development Foundation (ALS TDF), declared that it ‘exist[ed] purely to develop treatments for the patients living with ALS today, not to raise money for research papers’” (FRONTLINE, 2007).

In the above passage, today’s patient is described in terms of 1) now, the “‘patients living with ALS today,’” as well as, 2) the proactive nature of the new lay patient/caregiver community—comprised of guerrilla scientists willing to have a voice and start a foundation in order to “brashly set out to break the protocols of the drug discovery process…‘not to raise money for research papers’” (FRONTLINE, 2007).

This personal language played a large role in capturing the attention of patients and caregivers within the ALS community to not only participate, but more importantly, to raise money for the foundation. As one ALS caregiver, featured in the 2002 ALS TDF annual report, stated:

[My aunt’s ALS] prognosis offered her no hope and she was told nothing could be done. Shortly thereafter we discovered ALS TDF and its commitment to patients living with ALS today. We recognized increased funding would enable them to get equipment they needed, to hire top researchers and scientists, and to purchase SOD1 mice for drug studies…We have raised nearly $500,000 for ALS TDF over the last three years…[My aunt] is living her life with an incredible amount of hope, passion, strength, courage, and happiness. She gains this
strength knowing that ALS TDF is working to find a cure (Amy Whipple qtd. in, ALS TDF, 2002, pp. 9).

For Amy, the foundation’s “commitment to patients living with ALS today” personally motivated her and her family to contribute and believe in the foundation and the work it sets out to accomplish.

Just as WIIF’M depends upon personal motivations, professional and scientific justifications also prove to be crucial in the enrolling process. Upon comparing the foundations annual reports from 2000 (when it first launched) to 2005, one can see that an increase in expert testimonials occur—that is, more professionals are not only aligned with the foundation, but the foundation uses its professional members to establish credibility and attract more expert participation/collaboration. For example, in the 2000 report a total of two professionals are featured, with four in 2003 and then eleven mentioned in the 2005 report. The primary professional selling points the foundation advocated surrounded both ALS’ orphan status, and the foundation’s commitment to the process of validation and acceleration.

Orphan diseases consist of those conditions where the number of sufferers does not generate enough revenue and energy for industry and academics to pursue. That is, given the population, those diseases and conditions, which have a higher patient-base, such as cancer, are given a higher priority than diseases such as ALS. In describing his own personal connection with ALS, Steve Ascher states in his film:

Research scientists might spend years proving a theory that could lead to a drug….When Jeanne’s [Ascher’s wife and co-director, writer and producer of the film] mother was sick we had a front row view of traditional drug development. Six months after she died in 1995, the first ALS drug was approved. It’s called Rilutek and it extends the life of ALS patients by
about three months. Nine years later there was still no other approved drug. It seems like that’s an argument for at least some science to be done differently (Ascher qtd. in, Ascher & Jordan, 2006).

As such, given the disease itself, from a scientific standpoint, is novel, in that no cure has been found—this, from a professional stance, could excite experts wanting to make a direct change (as Dr. Tennore stated earlier in this chapter).

Correspondingly, the notion of validation and acceleration also provides novelty to the expert community. In 2000, Dr. Steve Gullans, a Harvard Professor and Director of the FDA2000 Project, describes the foundation, and the Heywood’s plight, as

“A unique organization because it takes a pro-active, participatory role in ALS research by identifying new avenues for therapy and assisting in both funding and performing the work. I enjoy collaborating with ALS TDF because it is a scientifically knowledgeable organization whose goal is to facilitate new research strategies that may be too high risk for more traditional funding agencies’” (emphasis added, ALS TDF, 2000, pp.2).

Dr. Gullans’ statement makes a direct reference to the scientific “enjoyment” he finds in “collaborating” with the foundation, as based not simply on its knowledge, but “new research strategies” and “high risk” capabilities. The high-risk research refers to the foundation’s determination to accelerate the speed of treatment research, by “identify[ing] both new and already-approved therapies efficacious in ALS using a quick, efficient system in the interest of ALS patients alive today” (ALS TDF, 2000, pp. 2). Similar to the concept of now, validation and acceleration, appeals to the professional interested in speeding up the traditionally slow process he/she may confront in the academic or clinical setting.
5.0. From Buying Mice to Selling [Your] Data—Introducing Part II of the Analysis

The concept boundary-breaking, in this case study, acts very much like a contribution to theories of social movements. A type of social movement practices involving specific places, technologies and techniques of relational (and strategic) stages of interaction. These practices work to break down the walls between the expert and the lay, while at the same time, establish a sense of credibility and expertise for each individual actor of the movement (medical professional and patient/activist).

In the first stages of the Heywood’s journey, boundary-breaking first presented itself as a personal fight, which became a team effort, paving way for a larger mission to be sold. In unpacking the initial steps in the Heywood’s journey to find a cure for ALS, one has to question the notion of the expert—as the expert can mean an amalgamation of a variety of individuals possessing a variety of skill-sets, experiences and viewpoints. That is, the data illustrates moments whereby the lay patient and/or caregiver-activist (the Heywood’s and those associated with their mission) adopt the behaviors of the experts, viewing medical knowledge production and the practice of medical research as the professionals do. At the same time, however, the data also reveals instances of collaboration and, even some cases of pushback between the lay and expert communities, where both parties express and contribute their own unique skills and knowledge to find a cure. Furthermore, the Heywood’s plight is repeatedly wrought with instances of controversy, dead-ends, and heated negotiations: in some instances, “[t]o a lot of scientists it seemed like [Jamie, in particular] was claiming that he, a non-scientist, was going to figure something out faster than anyone in the field” (Ascher & Jordan, 2006).
While the foundation used mice as the guinea pigs for testing a new form of accelerated research, the Heywood brothers’ next venture, PatientsLikeMe.com (PLM), focuses on the patient him/herself. Specifically, PLM emphasizes the importance of patients’ real-world and real-time data: self-reported medical history, treatment regimen (brand, dosages, both positive and negative effects), and personal accounts of the everyday life of living with a specific condition or disease. While, PLM relies on qualitative (in the form of PLM member forums), the emphasis of site is in its quantitative capabilities. Based on the many surveys and diagnostic tools a PLM member must fill out (in order to become a member and remain an active member), PLM’s true mission is to provide the largest database of measurable variables and numbers of its members in order to predict a patient’s disease trajectory, as compared to ‘patients like them.’

In a metaphorical sense, PLM works like a real-world laboratory: an online laboratory of patients freely talk in this online platform, taking a variety of diagnostic tests, while those behind the screen watch, learn, and…sell. As Natasha Singer argues in her 2010 New York Times’ article “When Patients Meet Online, Are There Side Effects?”

[T]he premise behind social networking sites like CureTogether.com and PatientsLikeMe.com, which offer online communities for patients and collect members’ health data for research purposes…[is to provide] ‘collaboration on a global scale [where] new treatments become possible…a system that allows you to think about personalized medicine’(Singer, 2010, pp.1). However, as Singer goes on to explain, PLM’s direct (albeit open) affiliation with pharmaceutical companies (their profit-generating clients), “pharmaceutical crowd-sources” as she refers to it as “raises important questions about the trade-off between the benefits of information sharing and the risk of patient exploitation” (Singer, 2010, pp.2).
Keeping these concerns in mind, the next chapter, examines boundary-breaking in the context of PLM; attempting to unpack who is actually breaking the boundaries between expert and lay: the patient or the new medical researcher. How does the Heywood brothers’ journey go from the personal fight to an arrangement of ‘mutual compliance’ among (and between) patients, industry, and researchers? Can Kristin Barker’s notion of physician-compliance be applied to this online setting, and thus, extend to a trend towards researcher-compliance, or is this just a new form of the age-old patient-compliance?
CHAPTER IV
A CASE OF BOUNDARY-BREAKING (PART II): FROM MICE TO PATIENT-GENERATED DATA

1.0. Introductory Comments: Onto the Next…Unmet Need

This chapter represents the second part of the case study and analysis of boundary-breaking. Taking the analysis from the creation of the non-profit foundation, ALS TDF, to the for-profit website www.PatientsLikeMe.com (PLM). The second half of the Heywood case study analysis illustrates how boundary-breaking differs when a lay person transitions into a type of expert. For instance, when the Heywood’s first engaged in challenging the medical system, they were considered lay. Thus, certain boundary-breaking strategies were enacted in order to establish some form of credibility (i.e. the initial stages of building ALS TDF). However, once the Heywood’s gain recognition, and to some extent, respect within the walls of the medical community, expert status develops and new forms of boundary-breaking can occur. Instances of boundary-breaking, or the ways in which medical professionals, patients or both use specific techniques and technologies to obtain information and knowledge, becomes even more complicated in a context that is complicated itself. Like a Petri dish of various compounds, PLM involves a multifaceted array of actors. Each actor engaged in unique and convoluted relationships and negotiations (i.e. patients-with-patients, patients-with-PLM, PLM-with-industry, patients-with-industry, industry-with-government, and PLM-with-government).

This analysis highlights the blurring of boundary-breaking stages (the personal fight, accruing a team, and marketing a mission), stressing how the transitions are neither smooth, nor sequential. Furthermore, once credibility is established, stages of boundary-breaking can in fact disappear. As the patient advocate becomes a new type of expert (as in the case of the Heywood
brothers), new demarcations of power emerge and boundary-breaking takes on different shapes. This chapter extends boundary-breaking into a context where a foundation of credibility and expertise has already been established.

Boundary-breaking in this context includes: 1) acts of information (or data) ownership and 2) specific use of patient data and, information, as a means of agency, control, or even profit. That is, how actors within PLM choose to use data can facilitate the recreation of boundaries. Additional layers of power between medical professionals and patient communities can arise. In the pages that follow, boundary-breaking is examined through four specific PLM examples. The first instance involves the co-founders as they attempt to differentiate their data from the data created by those within the healthcare system. The second occurrence of boundary-breaking involves two distinct types of PLM member-initiated activities, with patients enacting their own agency and control over their health and personal data. The third and final example looks at the power dynamics between PLM as an organization and those actors working within industry (i.e. pharmaceutical companies) and government (i.e. the Food & Drug Administration, FDA).

1.1. A Brief Overview: PatientsLikeMe.com (PLM)

In order to understand instances of boundary-breaking within PLM, we must first understand the context. Defining PLM is quite a difficult task. Some refer to PLM as a social networking website, large-scale patient support group or even a patient-advocacy site (Schonfeld & Morrison, 2007; Sheridan, 2008; Frost & Massagli, 2008; Huang, 2008; Borfitz, 2010; Brubaker et al., 2010; PatientsLikeMe.com, Tell the World Kit, 2010). While others define PLM as a Web 2.0 patient-generated research engine, or even a new form of accelerated clinical research, as based on its online data-sharing platform (PatientsLikeMe.com, Openness Philosophy, 2005-
PLM spawned from a 2004 conversation between three MIT graduates: the Heywood brothers, Jamie and Ben, and their long-time friend Jeff Cole. Launched officially in 2005 as a pilot, Stephen Heywood would be PLM’s first member in their first condition-based community: ALS. In a 2007 interview with PBS’ FRONTLINE, Ben Heywood describes PLM as “an idea that really came together when Jamie [Heywood] began dating online and realized that those services were essentially clinical assessment tools—something patients could use to find patients just like them” (Heywood, B., qtd. in, FRONTLINE, 2007, pp.1). Similar to any social networking site, members: 1) create a user name and personalized profile (i.e. Stephen’s name, “alsking101”); 2) fill out an ‘About Me’ section; 3) link to friends (or in the PLM case, a ‘Care Team’) and; 4) provide a general description as to why a member chose a particular community (i.e. the ‘Condition History’ box). PLM patient membership is free. Their business model: to sell anonymous and aggregated data of their PLM members to partners predominantly in the pharmaceutical industry.

Currently, the website houses a total of 15 disease/condition communities: each disease or condition categorized as based on its prevalence and rarity (see Figure 1). As of November 21, 2010, membership totals:

• **70,084** active and private patients (315 of whom are deceased): members choosing only to share their information to those within their specific community.
• **10,087** active and public patients (100 of whom are deceased): members choosing to make their profiles visible to anyone who visits PLM (member or non-member).

• **7,323** ‘Caregiver’ members, defined as “people actively involved in the care of a patient (home health worker, spouse, parent, child, etc even if that patient is not a PatientsLikeMe member” (PLM, “Patients: Select a Community,” 2010).

• **6,213** ‘Guests,’ representing PLM employees, friends, donors, and researchers; as well as, **44** ‘Admins,’ or various PLM staff members, including discussion moderators, community managers, and marketing officers (PLM, “Patients: Select a Community,” 2010).

Each community has its own membership requirements. However, no matter the condition patients go through a series of quantitative surveys and assessments that outline their past and present medical history. Qualitative information comes in the form of: 1) community forums and an internal community-based email system, where patients can speak to the community at large or engage in private conversations with individual community members; 2) a section within the medical assessment tools, where members can input daily commentary, symptom characteristics or personal notes. This emphasis on quantitative and number-based data becomes clear in the steps a patient takes in the process of creating an initial PLM profile. Once selecting a condition-specific community, members go
through a series of condition-specific surveys and questionnaires. These tools are rather reminiscent of those one might find while sitting in the waiting room of a physician’s office.

For example, membership into the PLM “Mood Condition Community,” involves a nine-step assessment process. This process consists of a combination of basic information, as well as a detailed account of a patient’s previous and current health information (see Figure 2). The “Health Information” portion of the process is the most detailed component of the profile creation. Each of the six sections requiring a member to fill out a battery of surveys and diagnostic tools that are either multiple-choice, Likert-Scale, or checklist-based (see Figure 3).

On the back-end, member information (both qualitative and quantitative) goes through a “curation process,” much like a library (Polk, Field Notes, 2010). Each symptom, side effect, treatment, and adverse event is pooled, categorized and analyzed by engineers, medical professionals, and researchers working for PLM. This process
allows for members to easily search the site for information specific to their current situation and needs. The ultimate purpose of these quantitative assessments: giving members the ability to see not only their disease trajectory in graphs and visual representations, but also to compare these results to other members of the community. Additionally, members are given the option to print out their profile in a two-page report. This report generates all the information a patient has input into the PLM system. Patients can bring this report to their physicians, with the goal of facilitating a collaborative and informed dialogue during a doctor’s visit.

With regards to boundary-breaking, these diagnostic tools represent instances where the PLM patient gets to see their disease trajectory and progress via charts, much like their physicians. However, unlike their physicians, they get to see their progress as it relates to patients like them. Furthermore, while physicians are able to know their patient-base (patients with similar conditions, diseases, symptoms and treatment option plans), individual patients are never able to know the information of other patients like them. HIPPA would never permit such exchanges. In the
traditional (or offline) medical setting, patient records are kept private, and only the medical professionals can see the charts of all patients in their practice. Yet, in the context of PLM, patients see the records of other patients. Record sharing allows for patients to compare, learn, and in some cases, apply the information of others like them to their own disease management plan. In this sense, patients get to see what physicians ordinarily do not: real-time and real-world data analysis of hundreds and thousands of patients suffering from the same condition. I also argue that PLM members get to see what clinical researchers rarely get to see in a traditional study setting. PLM members can see real-time pooled and analyzed data, at a speed clinical research cannot operate in (see Figure 4).

2.0. Boundary-Breaking & PLM Patient Members

Without patients, PLM has no foundation. Thus, a certain level of commitment to PLM patient members occurs. Patient-initiated boundary-breaking within the PLM communities largely surrounds data ownership. Data become points of controversy and leverage, as patients enact agency over their health by taking control of their medical information.
Instances of boundary-breaking, include how patients choose to use their data in order to challenge medical professionals (i.e. their physicians or even clinical research), as well as those working for PLM itself.

For instance, upon entering the website, PLM greets visitors with a homepage full of rotating PLM patient testimonials (see Figure 5). Notions of empowerment and a patient’s right to take control of his/her own health are prominent throughout PLM. According to one Multiple Sclerosis (MS) community member (see Figure 6): “I saw my neuro for the first time since joining PatientsLikeMe. Time spent and experience gained on this site armed me w/ [sic] info [sic] and made me feel that I had a network quietly supporting me…And it sure felt good” (MS Community Member, 2010).

By using words like “armed” and “support,” this PLM member illustrates how the website provided him/her with a sense of power, especially when confronting his/her neurologist. To feel “good” is to be “armed” with “info” and “support.” In this sense, data becomes synonymous with empowerment, agency and boundary-breaking.

With regards to taking control of one’s treatment plan, another MS member describes the frustration he/she had with his/her previous treatment plan (see Figure 7): “I wish [this site] was around years ago as I lost so much time and money doing what didn’t work” (Multiple Sclerosis Community Member 2, 2010). In a similar tone, this patient positions his/her use of PLM as a
way of gaining specific information regarding treatments. The data as empowerment theme resonates in this patient’s voice.

In this MS Community member’s case, he or she broke down treatment boundaries. By acquiring knowledge from other patients, this patient had the knowledge, power and agency to question and challenge the medications he/she had been taking. With each patient testimonial, the personal-amateur maverick emerges. The site provides the patient maverick with an ability to be informed and supported: “PLM empowers us” (emphasis added, PLM Member, “Mood Conditions Community,” 2010).

As Brendan I. Koerner put it in his 2009 Wired article “Forget Medical Privacy”:

Want to put your doctor’s stethoscope in a twist? Ask them to hand over a complete copy of your medical records…By converting our health data into electronic form and deploying it on sites like PatientsLikeMe…[p]atients can use the collective wisdom to research other ailments, investigate different treatments, and work with their doctor to improve their health (Koerner, 2009, pp.107).
PLM patient members break down the boundaries between their physicians and themselves by demanding information that is traditionally never supplied to them. Shifts in place (taking the medical record outside of the doctor’s file cabinet), technique (providing the patient with the ability to translate his/her medical history in ways the patient so chooses), and technology (recreating a condensed and online version of the physician’s record) occur.

In addition to challenging treatment plans, PLM patients also initiate instances of boundary-breaking in the form of clinical research. For example, in a 2010 TEDMed presentation, PLM co-founder, Jamie Heywood, describes one PLM patient: “humberto-from-brazil.” Humberto, like many of his fellow ALS community members, was curious about a 2008 Italian study. In this study, the researchers indicated that Lithium slows the progression of ALS (Fornai, et al., 2008). Humberto took the initiative and directly asked PLM, on behalf of the PLM “ALS Community,” to follow-up on these results. His request: “‘to help us answer this question [of whether Lithium actually works] because I don’t want to wait for the next trial, it’s going to be years. I want to know now. Can you help us?’” (Heywood, J., TEDMed, 2010). And PLM did. While the website “couldn’t run a clinical trial...[they] could see whether it was going to work for humberto” and other ALS members willing to take Lithium. In a quasi patient-generated clinical trial, 69 PLM ALS members started to take Lithium and track their results on the site. This case represents a clear example of a patient taking control of his health (and life) by taking a non-approved treatment for ALS (lithium) and asking for PLM to help in the process. As we will see later on in this chapter, the results of this PLM trial also illustrate how the PLM co-founders position themselves as experts. The co-founders do so by engaging in boundary-work when comparing their results to the results of the original study.
However, this is not the only example in which PLM members ask the website to take certain actions. In the case of the Lithium Study, patients asked for tracking tools. In another case of patient requests, members of the “HIV/AIDS Community” demanded that PLM take down a derogatory post on the community’s forum. Jamie describes this incident in a 2009 radio interview with Jon Udell of ITConversations:

**Jon Udell (JU):** Are there people in the system now who are taking the data out of it and doing their own work with it? Are they able to?

**Jamie Heywood (JH):** There’s no export function. I mean you can take your own data, but there is no data export function for other people…but you can scrape the site by hand…We’ve seen this in a couple of cases where people have started scraping data out and we’re like ‘ok, fine, here’s your tool.’ We have to give them the tool, otherwise they are going to scrape the data out then we are not meeting their demands.

**JU:** That’s how it works. They show you what they need and then to the extent that you can appropriately provide it in a way you will, right? That’s the way it should go.

**JH:** You’ll like this from a democratization standpoint. It hasn’t happened in a while, but every once and a while there’s personality blow-ups in the communities and there was one particular one around a sort of potentially offensive remark in the HIV/AIDS community. And we are sort of very much a, we don’t edit the expressions, we don’t edit speech in our site, we are sort of a very open platform. So unless it’s patently offensive or pornographic or really out of line we let it stand. And this is really a philosophical objection. And the patients got mad. And they started complaining and emailing us. And really there’s a vocal group of about 50 to 100 people, which was a substantial portion of the HIV/AIDS community in that time, and then they said, and someone figured it out ‘You know, the only thing they care about is our data, so let’s just start yanking our data.’ And they did. [laugh] They started yanking their data out of the system and we really had this meeting and you know, what do we do [laughing] we are being held hostage and you know if it had been a different issue I think we might have been, in this case, we really don’t believe in editing the content of the community, so you
know we stood on the philosophical grounds and we lost 25-30 people’s worth of data. And you know, that’s a lot, that’s a very valuable data set for us. So, they hit us, right where they knew where to hit us. And it’s great. I mean we loved it. We loved that our value proposition was so transparent that they knew how to exploit it [laughing] (Heywood, J., qtd. in, Udell [interview], 2009).

In the above case, HIV/AIDS PLM community members used their data, and namely, the act of “yanking their data” as a unique and new form of protest. If you do not comply with our wishes (by taking down the post) we will remove the one thing we know you need from us (our information).

In the patient examples described in this section, PLM patient members engage in boundary-breaking efforts. In the case of the testimonials, patients used the information they gained from PLM as a tool to challenge either the treatments they have been prescribed. Together, these practices facilitate a sense of empowerment. With the example of humberto and the PLM Lithium Study, patients with ALS took the initiative to try something that could potentially extend their life. With ALS, patients do not have the time to comply or adhere to the protocols of a traditional clinical trial. They need answers, and they need them now. The HIV/AIDS protest illustrates the power data can play in the game of compliance and negotiations between patients and experts.

While in the context of the foundation, the Heywood brother’s did not represent experts, in the PLM setting one sees that expert status has been gained in a unique form. That is, while patients can enact a certain form of control and agency over their data, those behind the scenes manage and code this data in order to create a sense of structure and organization. For instance, in response to the HIV/AIDS PLM protest, Dr. Wick’s brushed the incident off as “people
get[ting] mad and…lash[ing] out in whatever means they can…It’s a bit like when your four” (Wicks, qtd. in Polk [interview], 2010, pp.30). By reducing these actions to that of child’s play, a divide between the patient and PLM is created. As Dr. Wick’s goes on to explain:

Those that take their data away can take their data away and we’ve got enough numbers that that’s not crucial…If you were doing a small clinical trial and half your patients dropped out then you’re in trouble, but you know, for us, we’ve got thousands of people…I’d like everyone to stay, but it’s essentially a slightly self-destructive act. Because you probably spent hours over the course of weeks or months if you have a three star profile…it takes quite a bit of time to delete all the data at that point (Wicks, qtd. in Polk [interview], 2010, pp.30).

In order to understand the divide, one must understand the position in which PLM employees take with regards to their use of patient data.

3.0. Boundary-Breaking & the Co-Founders of PLM

For the Heywood’s, PLM represents a fuzzy mixture of a personal fight and a business of “filling a niche” (Cole qtd. in Polk [interview], 2010, pp.32). PLM was first created for Stephen Heywood: providing Stephen with a sense of support and a unique set of knowledge regarding his disease trajectory. In fact, Stephen references his profile in the documentary So Much-So Fast (see Figure 9). “I do have a picture of my progression. I am pretty much exactly on track” (Heywood, S., qtd. in, Ascher & Jordan, 2006). Stephen’s profile (the first on PLM) still remains on the website, and is often referenced in interviews with and presentations on PLM.

The technology behind PLM provided Stephen with a platform to connect to patients like him. More crucially, this online platform allowed for Stephen (and his family) to compare his situation (current treatments, medical history, and symptoms) to the medical history of other
ALS patients. In his interview with Jon Udell, Jamie references his “brother’s electronic medical record from Mass General, which is 173 pages” (Heywood, J. qtd. in, Udell, 2009). He goes on to argue that the Mass General record:

[C]ontained one-tenth of the information, let alone the meaning in the information, that is contained in [a] two-page summary on PLM. You get a sense of just how much we are trying to accomplish information compression…It’s essentially equivalent to reading a Wall Street Journal summarized statement of a company’s earnings…in an effective and compressed summary, versus reading 40 newspaper articles that each might contain one of the tidbits of information (Heywood, J. qtd. in, Udell, 2009).

Stephen’s profile allowed him (and his family) to obtain a concise version of Stephen’s medical history. The PLM report enabled the Heywood’s to understand Stephen’s condition without: 1) having to sift through a 173-page record created by medical experts, and 2) without having to translate the medical terminology permeating throughout the physician-generated record. In this example of the personal fight, boundary-
breaking practices include recreating a medical record that in the non-expert’s opinion (Jamie) is more informative than the expert’s version (Mass General). Furthermore, as we saw in the case of developing the foundation (see Chapter III), Jamie engages not only in boundary-breaking, but boundary-work as well (Gieryn, 1983). Jamie’s conversation with Jon Udell contains language that separates his record from the record created by the experts. In this separation, Jamie simultaneously uses language that reduces the quality and adequacy of the experts: Stephen’s Mass General record “contained one-tenth of the information” his two-page PLM report did (Heywood, J., qtd. in, Udell, 2009).

Similarly, when describing the case of “humberto-from-brazil,” Jamie clearly separates the expertise behind PLM (and the PLM Lithium Study) from that of traditional medical experts:

I can tell you that for those 69 people that took Lithium, they didn’t do any better than the people that were just like them…and that we had the power to detect that at about a quarter of the strength reported in the initial study. We did that one-year ahead of the time when the first clinical trial funded by the NIH for millions of dollars filed for futility last week and announced it…[Furthermore,] 10% of the people in our system took Lithium, 10% of the patients started taking Lithium, based on the 16 patients of data in a bad publication. And they call the Internet irresponsible (Heywood, J., TEDMed, 2010).

In the above statement, Jamie reduces the quality and credibility of medical professionals (i.e. the Italian clinical researchers), medical funding bodies (i.e. the NIH), and scientific publications (i.e. PNAS). While breaking down boundaries, Jamie recreates new boundaries. By creating these new boundaries and points of differentiation, Jamie (and indirectly his team at PLM) begins to take on a certain form of expert status.
Within the context of the foundation the Heywood brothers (Jamie and Ben) truly epitomize the lay patient activist (i.e. the personal-amateur maverick, as in Chapter III). However, in the case of PLM, their role on the team becomes complicated. For example, in Jamie’s interview with Jon Udell he directly states that his “background is clinical research…preclinical and clinical research” (Heywood, J., qtd. in, Udell, 2009). Similarly, on the website featuring Udell’s interview, Jamie is introduced as:

An MIT engineer…[who] entered the field of translational research when his brother Stephen was diagnosed with ALS…With experience in design, information technology, systems modeling, neuroscience, and industrial engineering, Jamie brings a unique perspective to drug discovery and medicine (Conversations Network, 2010).

His success in breaking down boundaries with the foundation enabled Jamie to enter the world of the experts, and become a type of expert in his own right. But, he is not a medical expert in the traditional sense. Rather, Jamie represents a new type of expert that aligns himself with medical professionals, while at the same time, intentionally separates himself from this expert community.

Upon looking at other PLM staff members, PLM as a new form of medical expertise becomes even more evident. In Figure 10, a list of PLM’s “Research Team” is presented. In just this one team, six of the seven members have a PhD, an MPH, or an RN behind their name. Many of these staff members came to PLM from industry (i.e. Richard Bradley spent years in working in the pharmaceutical industry) or from medicine itself (as with Sally Okun, who spent many years as a practicing nurse). The company takes great pride in their team of experts. The professional mavericks, each with their own connection to industry or medical establishments,
propel PLM into the larger “scientific discussion” (Wicks, qtd. in Polk [interview], 2010, pp.29).

In describing PLM, as compared to competitors like 23andMe.com, CureTogether, and WebMD, Dr. Paul Wicks, PLM’s Research & Development Director, states:

I don’t know of any of our competitors, 23andMe have one publication about some possible gene discoveries…you’re not seeing them publishing in peer-reviewed literature. So, they are not part of the scientific discussion. They are something else. They are Internet companies. We are a healthcare company. And that’s very intentional. The fact that 15% of our company are [sic] PhDs, you know, it’s an intentional focus and skew that we have (Wicks, qtd. in, Polk [interview], 2010, pp.29).

Dr. Wicks clearly emphasizes the expert backbone of PLM. In fact, it is the PLM experts that allow for Dr. Wicks to separate PLM from its potential competitors.

This emphasis on the PLM expert complicates the purpose of the website. *Who is in charge: the patients (who supply the website with their data) or the PLM researchers (who analyze this data)?* While patients freely enter their data, a team behind the scenes guides them. For instance, Sally Okun, PLM’s Health Data Integrity Manager, and head of the website’s “curation process,” describes her responsibilities as ensuring “that information entered by patients is accurately captured in our database. This is important for many reasons, not the least
of which is the need to be good stewards of the data entrusted to us by the patients” (Okun, PLM Profile, 2005-2010). Data organization is important, however, boundaries are created when the patients’ data is coded and reorganized behind the scenes. Jamie supports the above in the following statement:

We want to make this [the PLM charts, surveys and resulting analysis] all in the voice of the patient such that they understand it…it’s not about following medical ontology that sort of excludes the patient from the comprehension of their own illness, this is about making sure that the patient understands” (Heywood, J., qtd. in, Udell [interview], 2009).

In the above, the patient is positioned as lay. While PLM preserves the patient’s voice, the “structure” of PLM allows for experts to engage in research that the patients may or may not understand:

You know when we say we don’t know exactly what we are, I mean it’s this concept of a ‘structured information framework’ designed by a series of experts in your [the patient’s] illness that allows for the exchange of enough similarly pheno-typed information that we can compare and evaluate you [the patient] against everyone else like you in a useful way (Heywood, J., qtd. in, Udell [interview], 2009).

By describing PLM as having a “series of experts,” a new layer of power and demarcation between the PLM patient (the layperson) and the PLM staff member (the new expert) is created. This expertise and layer of power surrounds the credibility of data. While patients can engage in boundary-making and breaking practices as they control how PLM uses their data, PLM also has the ability to exercise power over the communities as well.

Data ownership becomes another point of leverage for PLM as they engage with industry partners.
4.0. Boundary-Breaking, PLM & Industry

As Dr. Wicks puts it: “you have to be in the business to change medicine” (Wicks, qtd. in, Polk [interview], 2010, pp.20). That is, in order to change the system you must be a part of the system. Staying true to their “Openness Philosophy,” PLM’s partnerships with industry partners is no secret. They make their business model and relationship with industry very clear throughout the website (i.e. the FAQs Section, in their Privacy Policy, and within the Terms & Conditions). Clearly, stated on their “About Us” page, PLM explains to prospective patient members:

Our operating costs will be covered by partnerships with healthcare providers that use anonymized data from and permission-based access to the PatientsLikeMe community to drive treatment research and improve medical care. We only share anonymized data with trusted partners and all our patient information is kept safe and secure. For more information, read our privacy policy (PLM, “About Us,” 2005-2010).

Currently, PLM has a total of 15 partners (PLM, “Partners,” 2005-2010):

- **5 Non-Profit Partners**: the Accelerated Cure Project for Multiple Sclerosis; the Myelin Repair Foundation; the National Kidney Foundation—Serving New England; National Multiple Sclerosis Society—Central New England Chapter; and the Parkinson’s Unity Walk.

- **6 Research and Academia Partners**: the Forbes-Norris MDA/ALS Research Center; the Northeast Amyotrophic Lateral Sclerosis Consortium; Penn State’s Milton S. Hershey Medical Center; the Pew Internet & American Life Project; the Robert Packard Center for ALS Research at Johns Hopkins; and the University of Wisconsin’s School of Library and Information Studies.

- **4 Industry Partners**: 23andMe.com; Avanir Pharmaceuticals; Novartis Pharmaceuticals Corporation; and UCB.
Just as PLM creates a boundary between itself and the patient, PLM also creates a wall between the patients’ data and the eager medical professional interested in acquiring this type of patient information. Partners must be granted access. In a rigid selection process, partners are screened and assessed before PLM decides to collaborate:

[W]e turn down a lot of business that has been put in front of us…There are hard and fast rules that we do and we do try to have a pretty good hard gut check on a lot of stuff like ‘This is of no benefit to anyone’…the ideal partnership is one where whatever it is that we are doing together benefits patients directly (Wicks, qtd. in, Polk [interview], 2010, pp.25).

In screening, PLM creates a boundary between its patients and its industry partners.

Partners beware: “if you are going to work with [PLM] make sure that your product doesn’t suck [sic] because [they] will find out and tell the FDA” (Wicks, qtd. in, Polk [interview], 2010, pp.27). Thus, PLM’s boundary-making efforts allow for data to not only act as leverage, but also surveillance over industry.

5.0. **Concluding Remarks: Boundary-Breaking or Boundary-Remaking?**

As a new form of expert, PLM is neither patient nor medical professional. PLM does not possess an entirely for-profit mentality; yet, non-profit it is not. In this sense, the website (and those behind it) become a unique layer of power. However, the power dynamics exhibited in PLM are not the same as those occurring in the traditional physician-patient or researcher-participant relationship. PLM represents a new type of power that creates (rather than breaks) different forms of demarcations between expert and lay. PLM acts as another hoop (and funnel) a patient goes through to have his/her voice heard. But, what part of the patient voice really makes
it through the system? After all, the patient’s voice is categorized, organized, coded and pooled into computable numbers.

Working outside and inside the walls of the medical community, boundary-breaking within the PLM setting is complex. Engaging patients enables PLM to generate a database akin to a “massive observational study…[that can act as a] good supplement to clinical trials” (Cole, qtd. in, Polk [interview], 2010, pp.34). For PLM, this database becomes a platform of leverage. While the site is created for the patient, PLM is still a business: “we are partially here as a business, but we are partially here to change medicine” (Wicks, qtd. in, Polk [interview], 2010, pp.19). Who is controlling whom? Is this a case of patient or lay-compliance, expert-compliance and/or mutual-compliance? In the final chapter of this thesis, the two case studies will be discussed, whereby boundary-breaking is unpacked against notions of compliance.
CONCLUSION:
THE COMPLEXITIES OF COMPLIANCE

1.0. Reviewing the Data: Boundary-Making, Breaking & Remaking

With the Internet and an increase in medical information accessibility, new types of medical experts come into being. A more diverse set of actors begins to contribute to processes of medical knowledge production and dissemination. Patients enter the scene in a new way, as they attempt to change the medical system at large.

The relationship between the medical professional and the lay evolves and shifts overtime, as each attempts to enact his/her agency. Inherent in enacting agency, compliance comes into play: specific actors with a desire to have others comply with their expertise and knowledge.

Traditionally, the non-expert (the patient) is expected to follow the recommendations of the expert (the physician): *patient-compliance*. That is, compliance within the medical setting generally requires the patient to follow the recommendations of the physician. In instances of boundary-breaking, however, compliance can shift back and forth between patient-compliance and *expert-compliance*. In her analysis of one online support group for Fibromyalgia sufferers, Kristin K. Barker highlights instances of *physician-compliance*. Physician-compliance involves patients demanding that physicians “accept [their] expertise” (Barker, 2008, pp.23). However, as my analysis of ALS TDF and *PatientsLikeMe* shows, Barker’s notion of physician-compliance can be elaborated upon to include three further cases of compliance: 1) *mutual-compliance*, 2) *lay-compliance*, and 3) *expert-compliance*.

Consistently in each type of compliance, data (a patient’s medical history and information) are center-stage. Data become points of leverage in the expert-lay, lay-expert, and expert-expert
relationships. The interactions between the medical professional and the patient represent dynamic power relations dependent upon information ownership (and accessibility). As information accessibility changes so too do: 1) the type of medical expert, e.g. a quack versus a physician; 2) the type of patient, e.g. a vocal narrator versus a passive subject; and 3) the development, acquisition and establishment of medical fact, e.g. fate in divine interventions versus results produced from controlled clinical studies grounded in the scientific method.

In Chapter I, historical and social factors influence shifts in place, medical technology usage and techniques of medical discovery. In an historical analysis, the first chapter provides an overview of the physician-patient and researcher-participant relationships. The analysis pays particular attention to how these relationships over time encouraged instances of boundary-making. Historically, boundary-making allows for individuals (those who come to be considered experts) to engage in both premeditated and unintended practices of demarcation. Dependent upon accessibility, demarcation involves the creation of walls between those with a selective type of medical knowledge (i.e. physicians) and those without (i.e. patients).

The importance of place or location of medical discovery rests in accessibility. Accessibility surrounds the capability to obtain, acquire and in turn, help in the production of medical information. Shifts in accessibility depend upon shifts in the information’s location (place). Those individuals who have access to medical information (and the necessary resources for its production) directly influence the creation of boundaries. For instance, in domestic medicine, information resided in the patient’s home. The clinic displaced the patient’s access to information from the home to the institutionalized clinic or doctor’s office. The use of new medical technologies (tools and resources for diagnosis and treatment purposes) facilitated a shift
from the patient’s narrative to the sounds and images of disease. Technology use became crucial in the practice of medicine. Direct dialogue between patient and physician (human-to-human communication) slowly became an indirect dialogue involving human-to-technology-to-human accounts. Changes in the techniques of diagnosis and treatment also contribute to expert-lay relations. During the time of domestic remedies, for example, the patient (and his/her caregivers) could, for the most part, engage in their own diagnosis and treatment procedures. Nevertheless, this emphasis on herbal remedies quickly competed (and lost) to the powerful abilities of pharmaceutical interventions used during the height of America’s Drug Revolution.

Boundary-making takes on many shapes and forms. In the context of the traditional physician-patient setting, the use of medical instruments like the stethoscope provide the physician with a more detailed and holistic knowledge of the patient. These practices facilitate instances where the physician knows information about the patient that this patient can never know or acquire in the same form. In the clinical research setting, study protocols mask certain aspects of a participant’s role in the larger study or drug trial. For instance, by contrast to the medical researchers, participants never know or understand their position in the study as compared to fellow participants. Much like the traditional physician-patient interaction, masking processes in the clinical research context facilitate boundary-making, albeit in different ways and forms. Where there is boundary-making, instances of boundary-breaking can potentially follow.

In Chapter II, I highlight instances whereby power negotiations between expert and lay occur. Efforts in making walls initiate practices of breaking these very walls down. Thus, making, in some instances, encourages breaking. For example, in finding a cure for ALS, the Heywood family needed to challenge the work of ALS experts to initiate change. Deep in the crevices of
demarcated walls between expert and lay one can find instances of power and credibility negotiations over the process of medical knowledge acquisition and production. Given the context, the time, and the personal stakes involved, power negotiations between expert and lay can involve both processes of exclusion (boundary-making) and inclusion (boundary-breaking).

The enactment of one’s agency, and particularly, the agency of the lay patient, make boundary-making and breaking, in a sense, co-dependent. To effectively break down walls of expertise and information accessibility, individuals often times engage in boundary-work (Gieryn, 1983). This involves the act of diminishing the credibility and expertise of others in order to bolster one’s own position of power. In applying the contextual landscape of boundary-making and breaking (Chapter I and II) to specific case studies (Chapter III and IV), the difficulty in differentiating boundary makers from breakers becomes evident.

This challenge of differentiation directly relates to medical information accessibility. Increases in access to medical information (as with patient online health-searching and medical record sharing) open the door for the emergence of boundary-breaking. Interestingly enough, in the case studies examined, despite an initial goal of collaboration between the medical community and patients, boundary-making simultaneously surfaces. At times, collaborative intent can be confused when practices of opposition and antagonism are employed. In contrasting what the lay communities know from what the medical community ‘thinks’ they know, boundaries are not necessarily broken, but recreated in new ways, in new forms and with new consequences.

For instance, in the case of the Heywood’s foundation, challenging medical practices paved way for: 1) the manipulation of old and traditionally slow techniques, as with a newly developed
accelerated mouse study model; 2) new use of technologies, such as combining drugs not ordinarily combined and/or even used to treat ALS; and 3) unique discoveries, such as the foundation’s recent findings concerning a new therapy that can potentially slow the progression of ALS (ALS TDI, “Press,” 2010).

However, as the analysis moves to PatientsLikeMe.com (PLM), new layers of power come into the picture. Once the lay-expert attracts attention and increasingly obtains credibility within medical professional circles (i.e. the Heywood brothers), their role in the lay community changes. Like the boundaries between expert and lay, those created between lay and lay seem to involve levels of information accessibility as well. Accessibility in this context deeply depends upon information ownership (those who possess ultimate control over the information and how this data is used) and data translation (the ways in which various parties manipulate, code and/or define specific patient information). For instance, in the case of the HIV/AIDS PLM protest, patients enacted their control by taking ownership of their data. Furthermore, PLM partners must go through a rigorous selection process before they can gain access to PLM datasets; thus, PLM enacts its control by taking ownership over the patients’ data. With regards to data translation, patients can upload their information, however, it has to be communicated in a very structured and specific way. Their information is managed via PLM templates and constructed surveys. Similarly, the curating of patient information also reorganizes and translates the patient’s original voice into a computable account: a variable.

In analyzing the data from PLM, lay hierarchies can be identified. For instance, a demarcation exists between those that openly share their medical history (the PLM patient member) and those
with the skills and opportunities to take this information and transform it into computable (and profitable) data (the PLM researcher).

Information ownership becomes a nebulous web of tensions between those who think they are in control and those that actually are (i.e. PLM members deleting data, the process of translating and recoding patient accounts, and the eventual selling of aggregated patient data to industry). As other actors are granted access to patient information, patient control and levels of expertise shift. While the PLM member’s voice contributes to an aspect of medical knowledge production, it does so in the hands of others. Similarly, data translation facilitates a divide between those that can understand a certain type of medical information (the physician’s medical record and the results of diagnostic tools) and those that need this information simplified (the two-page PLM report). As with Jamie and Ben Heywood, when lay members straddle between the role of patient or patient advocate and the role of expert, compliance becomes confused (and confusing).

2.0. Further Research: Mutual-Compliance, Lay-Compliance & Expert-Compliance

Traditionally, the non-expert (i.e. the patient) is expected to follow the recommendations of the expert (i.e. the physician). In instances of boundary-breaking, compliance can shift back and forth between patient-compliance and expert-compliance. As the PLM analysis shows, each actor involved (patients, PLM employees, and industry partners alike) holds a certain amount of control over other actors involved. That is, to some extent, everyone must comply with one another. Each actor holds a certain type of information and set of resources that others need and desire. For instance, PLM needs patient’s information, and in turn, patients need PLM to find
other patients like them. PLM also needs funding, yet, the company knows that they have something industry partners want: unique longitudinal datasets and unprecedented patient access.

In extending Barker’s physician-compliance, I introduce three new types of compliance. First, *mutual-compliance* involves cases where both expert and non-expert communities mutually adhere to each other’s set of unique skills and knowledge. For instance, in the case of the Heywood’s ALS foundation, mutual-compliance emerges when mavericks join together and depend upon each other’s unique sets of knowledge to enroll the larger medical system. As the foundation grew, so too did the mixture of expert and non-expert collaboration. Similarly, in the PLM context, the website must acknowledge the needs of their patient communities. *Humberto-from-brazil* represents a powerful example of mutual-compliance: patients requesting that PLM create a tool so that they can manage their health in ways they so choose.

*Lay-Compliance*, similar to patient-compliance, involves cases where the non-experts must adhere to the practices and techniques of the experts in order accomplish their goals. In the beginning stages of the Heywood’s foundation, the Heywood’s had to study the experts. They had to understand the experts’ terminology, their practices, and their drug testing techniques. In order to change the system, the Heywood’s needed to understand the system. In the case of PLM, industry partners (who consider themselves experts in their own right) must adhere to the selection process of PLM employees (individuals that the industry might not consider experts).

*Expert-Compliance* (a type that expands beyond just the physician) is defined as instances whereby varying degrees of experts must acknowledge and heed to the requests of non-experts, namely, patients. In the case of the PLM “HIV/AIDS Community” protest, members actively pulled all of their information off the website. In this sense, experts (PLM) who fail to comply...
with the wishes of their patients will suffer the consequences. Without data, PLM cannot exist. It is in the case of expert-compliance that a unique contribution to theories of social movements can be made.

A new type of social movement involving new places of protest, new uses of technology and unique techniques of data as leverage are emerging online. Further research in the area of boundary-breaking and specifically, expert-compliance might extend the literature in social movements. Compliance is an important concept to consider in the area of social movements and medicine, as it can impact the way in which institutions, such as medicine, work. For instance, compliance impacts disease trajectory: whether patients adhere to the specific treatment regimens prescribed influences how a disease might progress. Compliance also impacts the structure and success of clinical research: whether patients adhere to the study protocols or choose to remain in a study or trial from start to finish can skew results. Within the online context, how actors choose to disclose, use and/or manipulate information, paves way for unique instances of compliance negotiations. Data act as facilitators of boundary-making, breaking and remaking.
APPENDIX A: FIGURES REFERENCED

Figure 1: “PatientsLikeMe Community List”


Figure 2: “Sample PLM Profile Requirements”


Figure 3: “Sample PLM Diagnostic Tool: ‘The Mood Map’”


Figure 4: “PatientsLikeMe Community List”


Figure 5: “PLM Homepage”


Figure 6: “PLM Member Testimonial One, ‘Multiple Sclerosis Community’”


Figure 7: “PLM Member Testimonial Two, ‘Multiple Sclerosis Community’”


Figure 8: “PLM Member Testimonial Three, ‘Mood Conditions Community’”


Figure 9: “Stephen Heywood PLM Profile, ‘alsking101’”

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Figure 10: “Meet the Research Team”

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