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THE IMPACT OF SOCIAL NETWORKS ON HEALTHCARE

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INTRODUCTION

Ever since the internet became a household convenience the information available on the World Wide Web has grown exponentially (Brockman, 2011). Devices such home computers, laptops, and more recently smartphones and tablets, have allowed individuals to share, comment, edit and view this information. A common misconception is that the WEB and the Internet are one of the same thing (Brockman, 2011). The WEB is a “resource for speeding up the retrieval and dissemination of information” (Brockman, 2011, xxvii). On the other hand the Internet is the global network connecting computer device which enables the WEB. The WEB is a service within the Internet, which is the network (Brockman, 2011). It is important to make this distinction as confusion between networks and services has been a common mistake in the past. For example when electricity was first invented, people were so amazed by electric lighting they thought that was all they were buying, when electricity held so much more potential than just the light bulb (Brockman, 2011).

It is important to recognize this distinction in order to appreciate the true potential of the Internet, and how the WEB can and is evolving and improving. The initial form of the World Wide Web, WEB 1.0, demonstrated its capability for connecting and sharing information. So much so that it attracted patients, clinicians and researchers to use its service to share and access medical information. However access to information was not the first and last use of the WEB in healthcare. With the creation of social networks the WEB evolved into WEB 2.0, which paved the way for the internet to be used as a method of communication. In 2008 one third of Americans who were using the WEB to access research and information regarding their health used social networks *“to find fellow patients and discuss their conditions, and 36 percent of social network users evaluate[d] and leverage[d] other consumers’ knowledge before making health care decisions”* (Keckley & Hoffmann, 2010, p1).

Social networks have increasingly impacted healthcare through the development of health specific social networks, medical information available on websites and emerging technologies which track, gather and quantify medical data from patients in real time. The WEB can provide information which patients could not access in the past, giving them the power to educate themselves thus allowing them to partake in the decision making process of their own health. On the other hand, the industry, including physicians, researchers and pharmaceutical companies have gained access to new information which can help, cut costs, progress research, and improve the healthcare system. Whilst there are many potential benefits for the use social networks in healthcare, there are also many risks.

The following essay examines the risks and benefits for using social networks in health care. The essay explores the impact of the WEB in general as well as more specific health orientated social networks such as PatientsLikeMe. In a world becoming ever more interconnected and quantified, the aim of this essay is to identify the risks in order to determine how healthcare can achieve it’s the true potential.

CHAPTER 1: UNDERSTANDING WEB 2.0

1.1 A WEB 2.0 DEFINITION

In order to describe the impact of social networks on health care systems we must briefly understand the infrastructure upon which social networks are built on. Otherwise known as the internet, specifically its current interface, WEB 2.0, is the technological infrastructure that has allowed for social networks to exist. By understanding the services and technologies provided by WEB 2.0 one may begin to appreciate how it is contributing in the development of healthcare in the 21st century and its future impact. However, *“few concepts in information technology [which] create more confusion than WEB 2.0. The truth is that WEB 2.0 is a difficult term to define, even for web experts.”* (BMJ, 2006, p1283)

Nearly 50 years ago, at an MIT based enterprise, a team of computer scientists developed a large main frame computer which allowed up to thirty people to log on to it simultaneously from independent locations around the campus and even their homes and communicate with each other. This project was called Project

Mac (Brockman, 2011). Today this would be considered far from groundbreaking, as anyone can do this with a smartphone and 3G/4G or WI-FI signal (Brockman, 2011). If we try to remember the world without the internet, we could appreciate it as a work of genius and arguable one of mankind's greatest achievements (Brockman, 2011).

"The most remarkable quality is that it was constructed not by one individual genius...nor by a top-down company such as Sony or IBM, but by an anarchist confederation of largely anonymous units located all over world, [with] no one massive central computer with lots of satellites...[but rather] a distributed network of computers of different sizes, speeds and manufactures. A network that nobody, literally nobody ever designed or put together." (Brockman, 2011, p9)

Unlike project Mac, Internet is not a central computer used by an individual to simply plug into. It is rather the product of a series of developments in computer hardware and software which lead to its eventual creation (Brockman, 2011). It evolved into existence much in the same way as an ecosystem is created as an outcome of different variables coming together. In the case of Internet, different innovations in network infrastructure came together with the need for scientists to easily communicate and exchange their work, leading to its creation (Abbate, 1999). Berners Lee, a scientist working in CERN, aiming to facilitate the communication between fellow researchers, created an interface which allowed the existing network infrastructures to connect with each other (Abbate, 1999).

Berners Lee's interface, along with the appropriate web software provided by personal computers boost the creation of browsers that made it popular not only among scientist in CERN but other institutions too, allowing easy access to the internet (Abbate, 1999). This interface was given the name World Wide Web (Abbate, 1999).

"The World Wide Web (WWW) was intended to be used to share ideas and promote discussion within a scientific community."

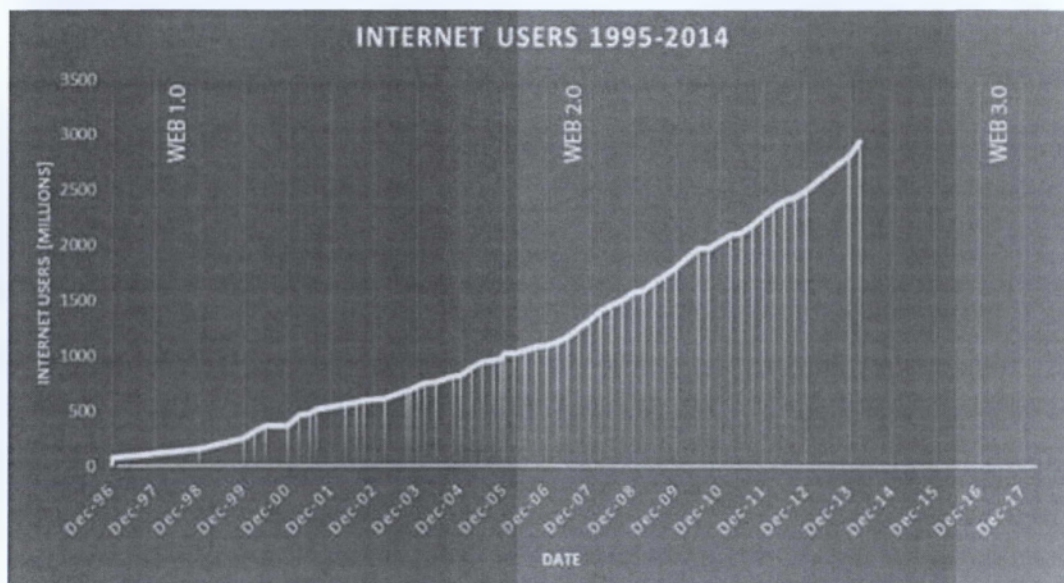
(Boulos & Wheelert, 2007, p2-3)

The creation of World Wide Web, or in short the WEB, suddenly provided an alternate method of sharing ideas. It is quite similar to a giant encyclopedia, but

different from the traditional encyclopedias as they were rigorously edited by experts (Brockman, 2011). With the creation of the Web anyone who knew how to create a website had a new medium to publish his or her ideas without having to go through publishers and editors. The problem was that websites were initially difficult to create by the average individual. In the mid 90's most people probably did not have the computer skills to create and manage their own website, as there were far fewer household computers, not to mention the absence of smart phones and laptops. However the WEB revealed the potential to break through the boundaries of publishers and professionals in order to share ideas on a global level with the readers assuming the role of the editor and critic (their BMJ 2006). Its obstacle was in communication and editing as there was no easy way for a websites reader, or multiple readers, to engage with each other in discussion over the content of the website (Boulos & Wheelert, 2007). The WEB at its early stages shared the same shortcoming as traditional encyclopedias did, meaning an abundance of information, but a lack of interactive communication (Boulos & Wheelert, 2007).

In time this obstacle was overcome, due to the emergence of the WEB's successor, WEB 2.0. In essence WEB 2.0 evolved from the original WEB as an enhancement, rather than correction of the previous shortcomings (Boulos & Wheelert, 2007). As computer devices evolved into smartphones, laptops, etc. and internet connections got faster and easily accessible through Wi-Fi, the communication boundaries of the internet were overcome through a range of online software which facilitated the direct dialogue between web-creator and web-reader

Table 1 Data collected from Internetworldstats.com, Accessed 15-08-2014



as well as the dialogue between mutual web-readers. Suddenly it became easier not only to share ideas through the web but also to discuss them via blogs, podcasts, wikis and social networks (BMJ 2006).

The aforementioned table presents internet users from near the start of its launch to general public in 1995 at 16 million users, around 0,4% of the world's population at the time, till today's estimated users of 2,9 billion, around 40% of the world's population. One notices the steady rise in users in the encyclopedic era of WEB 1.0 as the internet's ease of access to information become ever more popular, but in 2006 with the progression to WEB 2.0 this rise of users suddenly accelerates. This shows that the technological breakthrough of WEB 2.0 allowed for a range of new services which attracted innovation, investment and consequently more users. An intrinsic characteristic of WEB 2.0 is the ability for a subject published online to be edited by the readers themselves as in the case of Wikipedia (Boulos & Wheelert, 2007). This has led to its unique quality and advantage over alternative sources of information and communication. Through WEB 2.0 the internet was no longer static and unchanging (Boulos & Wheelert, 2007).

As a result of the services provided through WEB 2.0, this *"second incarnation of the WEB has been called the 'social Web', because, in contrast to WEB 1.0, its content can be more easily generated and published by user"* (Boulos & Wheelert, 2007, p2). WEB 2.0 allows for the internet to truly function as an eco-system constantly developing through the input of its users. It evolves and corrects its content through the discussion of millions of people that simultaneously participate in the global debate of collective intelligence forming what is now known as the 'online' community (Boulos & Wheelert, 2007). Skeptics argue that the creation of WEB 2.0 along with the amount of constantly edited information that can be spread to billions of people will lead to the growth of the collective intelligence of the human species. (Boulos & Wheelert, 2007).

"Web 2.0 emphasizes the pre-eminence of content creation over content consumption. Information is liberated from corporative control, allowing anyone to create, assemble, organize, locate and share content to meet their own needs or the needs of clients" (Boulos & Wheelert, 2007, p3)

Table 2 - Characteristics of WEB 1 and WEB 2 © Boulos & Wheelert, 2007, p3

Web 1.0	Web 2.0
Encyclopedia Britannica http://www.britannica.com/	Wikipedia http://en.wikipedia.org/
Personal Web sites	Blogs (Web logs)
Publishing (Content Management)	Participation
Taxonomies	Folksonomies
Directories	Tagging
'Stickiness'	Syndication

In short, WEB 2.0 is the evolution of the internet into its current state of an interactive form of communication between users in order to share information and knowledge on a global level. Whilst its initial version, WEB 1.0, provided a groundbreaking way of sharing and accessing information, WEB 2.0 facilitates communication and constant editing of published information allowing for that the WEB's content to be discussed and developed, making WEB 2.0 "...*about conversations, interpersonal networking, Personalization and individualism [in other words the] 'People-centric Web.'*" (Boulos & Wheelert, 2007, p3).

1.2 THE EMERGENCE OF THE WEB 2.0 IN HEALTHCARE

As the use of WEB 2.0 became so wide spread, its impact on society, institutions and industry along with its interactivity calls for the return to Berners Lee's original intent as a line of communication for people to promote and share ideas and information (Abbate, 1999). This impact has been witnessed in the health care industry as studies revealed that patients with few options who now have access to the WEB, no longer wait for mainstream science to design studies, measure, analyze and report (Frost et al., 2008). Furthermore, Internet is not solely being used to search for information about disease and treatment, which was the internet's capacity during WEB 1.0 (Frost et al., 2008). Nowadays online disease-focused communities are being formed to share and organize personal experiences in an effort to harness their own experiences in service to achieving better healthcare awareness, and consequently healthcare outcomes (Frost et al., 2008). This prompts for *"significant changes in the ways the World Wide Web is being used in health care and education"* (Boulos & Wheelert, 2007, p3).

In the late 90s, websites featuring health-related information for the first time were more frequently visited than online adult content (Ballas, 2001). This sparked an interest in the private sector to invest in online healthcare services, making them "some of the hottest 'picks' on Wall Street in 1999 ... *"e-healthcare companies" like drugstore.com, MedicaLogic, DrKoop, and Gomez.com"* (Ballas, 2001, p79). These companies had a range of products from providing *"healthcare-related statistical information to fully electronic medical records."* (Ballas, 2001, p79). Nearly \$900 million was invested in software and technology services focused on health care in 2007, the latest year for which data are available (Hawn, 2009). This expansion of the Healthcare industry into the WEB led not only to investment opportunities but changes in the dynamic of the doctor - patient relationship. A survey carried out in 2003 on 1050 physicians showed that 85% of the physicians who responded had patients who brought to them medical information they found on the internet (Murray et al., 2003). As the WEB providing a new source of information for patients, new communication channels were established within the healthcare industry thus creating a market for such services to be setup up efficiently.

Table 3 - Most popular web 2.0 applications © Deloitte Development LLC, 2010

MOST POPULAR WEB 2.0 APPLICATIONS			
Network	Description	Usage	Business Applications
Twitter	140-character news feed	290 million users (2014)	• Posting press release-like announcements which
Facebook	Recreational peer-to-peer social network	1.2 billion users (2014)	• Building fan pages for specific causes
YouTube	Video	1 billion unique users per month (2014)	• Posting educational videos and testimonials
Blogs	Internet web diary	175 million blogs (2014)	• Discussing happenings in an organization
LinkedIn	Professional peer-to-peer networking	313 million users (2014)	• Recruiting talent, announcing staff news
Wikis	Tool that allows groups to create and edit pages of content	1.75 billion contributors (2001-2014)	• Enabling knowledge management
Forums and discussion boards	Online locations to post questions and receive community replies	20 percent of surveyed Americans have posted on bulletin boards	• Facilitating participants' sharing of experiences and knowledge

PATIENT-DOCTOR DYNAMIC

In the survey mentioned above, 61% of the respondents used Internet to search for scientific articles and information or to e-mail colleagues (Murray et al., 2003). It would appear that the encyclopedic side of the internet, which emerged with WEB 1.0, attracted physicians and patients for its easy access to medical information. However, some physicians observed another opportunity for the use of WEB 2.0 software in healthcare. Dr. Parkinson, a 32 year old clinical associate who runs a primary medical practice in New York, expanded his own practice into the WEB as he witnessed that potential (Hawn, 2009). Dr. Parkinson recognized a fundamental flaw in patient-doctor communication which was rooted in the failure of medical practices to evolve communication networks in parallel with the actual evolution of communication itself. With respect to WEB 2.0.

“Our profession, at its core, is fundamentally flawed relative to how today’s world communicates and function [...] the infrastructure of health care needs a total repair from the ground up. It needs to be Facebook-ed [and] wiki-ed [...] after all, at the heart of health care is communication between clinicians and patients, something most of U.S. health care is still conducting with the technologies of the twentieth century at best.”

(Hawn, 2009, p362)

Dr. Parkinson appreciated that *“the internet is changing the status quo by providing interpreted medical information directly to the consumer”* (Ballas, 2001, p80). Previously, when a patient required to undergo an invasive procedure, the patient’s decision was determined mainly by the information given to him/her by his physician and any information beyond that was sourced from friends and family, and maybe a second consultation with another physician (Ballas, 2001). In essence, the decision came down to how much trust the patient had on his physician, giving the physician power over the patient’s decisions (Ballas, 2001). Of course if the patient doubted his physician’s diagnosis he could leave. However given the time and effort it takes to develop such a personal relationship with one’s physician and switching to a new physician would mean dealing with a practitioner unfamiliar to one’s medical history, the patient might think twice before switching doctors (Ballas, 2001).

“VICTORIA SCHLESINGER, 31, the chief counsel for Telignet Communications Company [...] was told by her physician that she might have lupus. Pressed for time, the doctor declined to elaborate until the lab results were back. Victoria went to her computer, typed lupus in a search engine, and found out all that she needed to know. Later, she went to her physician informed, and asked for her test result. She did not have the disease, but did not keep that physician.”(Ballas, 2001, p80)

It could be argued the physician made the above decision, as a medical professional aware of the implications of having lupus, to avoid causing stress to the patient before having test results confirm such a diagnosis. However it can also be argued that it is the patient’s right to be informed of any possible health complications the physician might be concerned with, with all relevant information provided, thus keeping the patient informed and in control over their own health.

Bottom line is that in past, when it came to medical information, patients were restricted to their only reliable source being the information provided by their physician. With the expansion of healthcare information available online, the relationship between patients and physicians is changing, becoming more balanced and symmetrical (Ballas, 2001). A professional healthcare partnership so to speak, as health information is become easier accessible to patients.

“This information is now available in a format that is not just physician-friendly but patient-friendly as well. Patients who use the web are becoming more educated about their medical decisions. They no longer come to the physician for medical information, but rather to seek medical advice to confirm their suspicions.” (Ballas, 2001, p80)

There are many tools online which can be used or even are created specifically for healthcare purposes whether it is *“to facilitate the search for information on new medical developments [or to] connect like-minded patients”*(Frost et al., 2008). The healthcare industry is beginning to embrace WEB 2.0 as a new platform to engage with and support patients and *“across the health care industry, from large hospital networks to patient support groups, new media tools like weblogs, instant messaging platforms, video chat, and social networks are reengineering the way doctors and patients interact (Hawn, 2009).*

Table 4 – WEB 2.0 Software Application in Healthcare ©Deloitte Development LLC., 2010

WEB 2.0 SOFTWARE APPLICATIONS IN HEALTHCARE		
Health care application	Participants	Impacted organizations
Maintaining health and wellness	<ul style="list-style-type: none"> • Consumers • Health coaches 	<ul style="list-style-type: none"> • Physicians • Health plans • Wellness facilities • Hospitals • Alternative providers/health coaches • Employers
Disease management	<ul style="list-style-type: none"> • Consumers • Physicians • Allied health professionals 	<ul style="list-style-type: none"> • Physicians • Retail clinics • Health plans • Device manufacturers • Drug companies • Alternative care providers • Disease management companies
Clinical trial recruitment	<ul style="list-style-type: none"> • Consumers • Clinical investigators 	<ul style="list-style-type: none"> • Academic medicine • Drug & biotech companies • Contract Research Organizations (CROs) • Device manufacturers
Personal Health Records (PHRs)	<ul style="list-style-type: none"> • Consumers • Health professionals 	<ul style="list-style-type: none"> • Drug & device manufacturers • CROs • Academic medicine • Health plans
Health professional training	<ul style="list-style-type: none"> • Physicians • Advanced practice nurses • Allied health professionals 	<ul style="list-style-type: none"> • Drug & device manufacturers • Licensing organizations • Hospitals • Schools
Public health announcements and campaigns	<ul style="list-style-type: none"> • Consumers • Regulators 	<ul style="list-style-type: none"> • Regulatory agencies • Public health agencies • Local/state/federal government
Treatment, physician or hospital selection	<ul style="list-style-type: none"> • Consumers 	<ul style="list-style-type: none"> • Drug & device manufacturers • Hospitals • Health plans • Retail clinics

Table 5 illustrates two categories created for the purpose of this essay in order to further analyze the impact WEB 2.0 applications may have Healthcare. One category focuses on the use of WEB 2.0 applications to find and gather healthcare related information, whilst the other category refers to the use of WEB 2.0 as a line of communication for patients and physicians in order to share experiences and ideas. It is important to access the impact of these two categories in order to determine *“how are patients and caregivers [becoming] organized around [the] shared medical data [they] are finding, collectively evaluating, and using [this] information to inform treatment decisions and drive change in medical discovery and translation to treatment”* (Frost et al., 2008, p217).

Table 5 - Possible healthcare application of current WEB 2.0 software

	WEB 2.0 SOFTWARE	HEALTH CARE APPLICATION
WEB 2.0 AS A SOURCE OF INFORMATION	<ul style="list-style-type: none"> • WIKIS • JOURNALS • BLOGS 	<ul style="list-style-type: none"> • Maintaining health and wellness • Health professional training • Treatment, physician or hospital selection
WEB 2.0 AS A LINE OF COMMUNICATION	<ul style="list-style-type: none"> • FACEBOOK • TWITTER • LINKEDIN • FORUMS 	<ul style="list-style-type: none"> • Maintaining health and wellness • Disease management • Clinical trial recruitment • Public health announcements and campaigns • Treatment, physician or hospital selection

CHAPTER 2: WEB 2.0 AS A SOURCE OF MEDICAL INFORMATION

2.1 - WIKIS AND COLLABORATIVE WRITING

Collaborative writing is a category of WEB 2.0 which allows users to create content which subsequently can be edited by anyone who reads it (Archambault et al., 2012). It is a form of social media which has witnessed noticeable popularity in recent years even within the health care sector (Archambault et al., 2012). Also known as WIKIS, collaborative writing has accepted attention among physicians and patients as a quick way for accessing and sharing knowledge (Archambault et al., 2012). Different wiki websites have different methods of collaboration, which vary on how strictly the content posted is edited and reviewed by experts, as well as limiting access to who can upload or edit an article (Archambault et al., 2012).

Although Wikis might be considered open to editing by any reader it actually is a *"common observation in large public wiki projects like Wikipedia [...] that only a very small fraction of users contribute [to] most of the content, while the majority of visitors are lurkers, merely visiting and experiencing the community passively"* (Boulos & Wheelert, 2007, p5). Nonetheless, Wikipedia constantly updates its medical articles making them available in 271 languages and viewed 150 million

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Table 6 - List of popular medical WIKIS © HLWIKI Canada, 2013

NAME	SUBJECT MATTER	AUDIENCE	CONTENT	Collaborators
Aids wiki	Gathering place for aides dissidents and activists	Activists, general public	2,525 pages	Registered Users
Ask Dr wiki	Nonprofit educational website. Articles, clinical notes and medical images	Physicians, residents, and medical students	1,369 pages	Clinical professionals, credentials required
Cancer Guidelines Wiki	Cancer clinical practice guidelines	Health care professionals, public health specialists, consumers	1038 pages	Selected Authors, General Public may only comment
GANFYD	Medical Knowledge that anyone can read	Healthcare professionals, public	7,070 pages	Qualified doctors from the UK, Canada, New Zealand and Australia
HLWIKI international	Health librarianship, social media and current information technology topics	Information Professionals, librarians, health professionals, social media experts	1,000+ pages	Registered Users Most health Librarians
OpenWetWare	Sharing information for researchers working in biology & biological engineering	Biology and biological engineers	17,092 pages	Applications are individually evaluated
Psychology wiki	Up-to-date and accurate psychology information	Health workers, psychologists, students	60,399 pages	-
WIKI DOC	Medical news service and textbook of medicine that anyone can edit	-	71,501 pages	Anyone who registers
Wikisurgery	Free Surgical encyclopedia hosted by the International Journal of Surgery	Surgeons and their patients	1,609 pages	contributions can be made by those who register, confirm their email address and whose application is accepted
Wikipedia: WikiProject Medicine	A place where people interested in medical and health content on Wikipedia can discuss things, collaborate, or debate related issues.	525 registered medical professionals	32, 099 articles ranked based on importance and integrity	Health Professionals, Physicians, General Public. No registration required to view content

times per month (Archambault et al, 2012). Wikipedia offers a portal dedicated to medical articles, whose registered collaborators are, as of August 2014, 354 medical and health professionals with confirmed credentials (Wiki-project Medicine, 2014). This might explain why according to recent studies *“70% of junior physicians use Wikipedia in any given week, that 50% to 70% of practicing physicians use it as a source of information in providing care, and that 35% of pharmacists refer to it for drug information”* (Archambault et al., 2012, p2).

Wikis have emerged as a valuable tool for health professionals facilitating as a global platform for different medical professions to promote and share new ideas and innovative practices to such an extent where wiki tools are being used for the mass collaboration in mapping the human genome (Archambault et al., 2010). However for collaborative tools to function beneficially in health care sector, they must be constantly peer-reviewed and updated in order to maintain the integrity of the information published (Archambault et al., 2010). As wikis become even more popular among medical professionals and patients, the safety of the content published is constantly called into question for its reliability due to its lack of ‘traditional authorship’ (Archambault et al., 2010).

Nevertheless, the use of Wikis in health care “returns to the idea of using software to create optimal knowledge building opportunities for doctors.” (BMJ, 2006, p1283). The increased popularity of collaborative writing show untapped potential in the area of healthcare, as websites such as Wikipedia are experimentally operated yet highly successful projects such as ‘WikiProject Medicine’ allowing free access to abundant medical articles continually updated by registered professionals. Therefore can the content every be 100% reliable in a science so heated in debate among professionals and how may this sudden ease of access to information affect the doctor-patient dynamic with respect to quality of healthcare? (BMJ, 2006)

2.2 MEDICAL BLOGS

In general, Blogs are applications which have authors who identify themselves and even share personal content such as photos and videos. Often, readers have public access and can post comments visible to others (Westbrook, 2007). By 2010 there were an estimate of 112 million blogs across the WEB (BMJ, 2006). Blogs of relevant content or generally interlinked with each other and the *“through hyperlinks and the global network of blogs is refers to as the blogosphere. Blogs are often thought as analogous to online diaries, but this is a misconception”* (Westbrook, 2007, p196). Blogs are more like personal webpages dedicated to a specific subject matter or theme, as initially blogs they were personal lists of web content by later with software development began including other forms of multimedia (Westbrook, 2007).

Hospitals have recently been using blogs to receive feedback and customer ratings, as well as more detail accounts of patient’s experiences (Vikram, 2010). The information gathered can then be used for the hospital to improve its services as well as promote itself to future customers who appreciate other patient’s reviews as oppose to mainstream advertising (Vikram, 2010). Many blogs have information about different therapies as well as preventive measures and awareness campaigns in an effort to reduce costs for the hospitals itself, patients, public or private insurance companies (Vikram, 2010). With the ability to insert comments patients can then leave their feedback on the blog that is visible to other readers as a reference for the hospital (Vikram, 2010).

With regards to personal blogging web spaces in health care, there are two categories, implicit and explicit (Westbrook, 2007). Implicit blog content tend to be general topics, with links to other discussing healthcare issues on a general impersonal level without going into detail about personal experience (Westbrook, 2007). On the other hand, explicit refers to blogs which discuss specific medical issues of direct impact to the author, such personal experiences with *“a chronic disease such as leukemia, self-management of a disease such as diabetes, documenting a specific trajectory such as pregnancy, or to support attempts to achieve the specific health care goals such as losing weight or smoking cessation.”* (Westbrook, 2007, p196).

Table 7 - Top 10 ranking healthcare related blogs globally © edrugsearch, inc., 2014

RANKING	NAME	DESCRIPTION
1	KevinMD.com	Social media's leading physician voice.
2	ScienceBasedMedicine.org	Dedicated to evaluating medical treatments and products of interest to the public in a scientific light
3	Well – The New York Times	The New York Times Well is a blog by Tara Parker-Pope on the latest medical research and societal trends affecting your health.
4	medGadget	Internet Journal of Emerging Medical Technologies.
5	Respectful Insolence	The miscellaneous ramblings of a surgeon/scientist on medicine, quackery, science, pseudoscience, history, and pseudo history (and anything else that interests him).
6	Cato @ Liberty	Promoting an American public policy based on individual liberty, limited government, free markets and peaceful international relations.
7	DiabetesMine	The all things diabetes blog: "A respected site that helps you keep up with what's moving and shaking in the diabetes world" -- says NY Times' About.com
8	PharmaGossip	Looking beyond the spin of Big Pharma PR. But encouraging gossip. Come in and confide, you know you want to
9	Pharma Marketing Blog	An independent monthly electronic newsletter focused on issues of importance to pharmaceutical marketing executives
10	Booster Shot – LA Times	Oddities, musings, and news from the health world.

Another application for the information gathered through healthcare related blogs is its use for the improvement of healthcare policy (Westbrook, 2007). The patient's role becomes more active in policy making with the patients evolving from information consumers to information producers (Westbrook, 2007). Through monitoring the feedback of patients, physicians, stakeholders or active participants in the subject matter governments, industry and healthcare professionals can interpret and correlate this information to fine tune their services (Westbrook, 2007). This dramatically changes the role of blogger directly impact health care decision making (Westbrook, 2007).

"Patient's [in] managerial roles, this extends far beyond managing their own health. Blogs also transform in this regard to something more than a personal space they follow changing trends in business practice"

(Westbrook, 2007, p201)

Therefore, blogs offer an organized source of information for patients to freely access related content and personal experiences of people directly affected by subject matter interest. However beyond this, blogs also offer a valuable insight through the feedback they offer to hospitals, companies and policy makers. This feedback shapes the healthcare industry from a bottom up approach impacted by the patient or active participant. The question rising with democratization of health care information via blogs is how does the patient distinguish the experts opinion from the average person's personal account, and how reliable is that information? (Westbrook 2007) If all published information, whether clinically right or wrong, can reach a point to impact decision making is the democratization of health care a positive aspect?

2.3 MEDICAL JOURNALS

When people think of journals they think of hard to understand, sometimes boring, and scientific essays shared within the scientific community to promote and discuss new findings and research (Smith, 2006). The science which support medical progression is published in journals, for example the British Medical Journal, which is internationally peer reviewed, "*published some of the first studies in anesthesia, on the cause of malaria, and on linking cigarettes to lung cancer*" (Smith, 2006, p115). Medical journals deeply influence healthcare practices, not only affecting the methods of treatment doctors may use on their patients but may also form part of the decision making process for policy makers and private companies (Smith, 2006).

Moreover, medical journals existed long before WEB 2.0 applications dating back to the 18th century, gradually expanding to cover all aspects of health care, medicine, and biology (Smith, 2006). Its legitimacy and advantage over traditional medical textbooks, is that the content often goes through a peer review process which involved other medical professionals to review and critique the authors findings and conclusions before it is published (Smith, 2006). Till before WEB 2.0 applications, medical journals benefited patients indirectly as they were not easily accessible for patients to read. Rather they were intended for doctors, who intern improved on their methods which was of benefit to patients (Smith, 2006). In nowadays, journals published over WEB 2.0 applications, have expanded online allowing patients to access the same information as doctors do, with evidence showing journals are facilitating patients and doctors to make decision together, leaving the patient feeling secure and more satisfied with his decision (Smith, 2006).

However journals also have an obscure side which involved financial gain for publishing companies and career boosters for research, calling into question the specific goal of a journal as well as the legitimacy of the content published.

"That's when I thought the role of journals was to educate doctors! Journals are not for clinicians. They serve authors and the research community, not readers. This is not a totally cynical view. Getting published in the right journal has a certain prestige and can guarantee university tenure or progress an author's career." (Smith, 2006)

Table 8 - Top journals ranked by impact factor © Online-degrees-today.com, 2014

RANKING	NAME	DESCRIPTION
1	New England Journal Of Medicine	English-language peer-reviewed medical journal published by the Massachusetts Medical Society. It is the oldest continuously published medical journal and influential general medical periodical in the world.
2	JAMA: Journal of The American Medical Association	Published since 1883, is an international peer-reviewed general medical journal promoting the science and art of medicine and the betterment of the public health.
3	BMJ (British Medical Journal)	An international peer reviewed medical journal and a fully "online first" publication.
4	Pediatrics	The official peer-reviewed journal of the American Academy of Pediatrics. This publication serves authors and readers of the general medical profession.
5	Circulation	An American Heart Association journal that is aimed at an audience of cardiologists, cardiovascular surgeons, electro physiologists, internists, nurses and others interested in cardiovascular medicine.
6	Journal o Infectious Diseases	This publication represents physicians and other health care professionals who specialize in infectious diseases.
7	Brain: A journal of Neurology	Provides researchers and clinicians with the finest original contributions in neurology. Leading studies in neurological science are balanced with practical clinical articles.
8	CA: A Cancer Journal for Clinicians	This is a peer-reviewed journal of the American Cancer Society providing cancer care professionals with up-to-date information on all aspects of cancer diagnosis, treatment, and prevention.
9	Clinical Infectious Diseases	One of the most heavily cited journals in the fields of infectious diseases and microbiology publishes articles on diverse topics in infectious diseases, with a focus on clinical practice.
10	Journal of the American College of Cardiology	Publishes original peer-reviewed clinical and experimental reports on topics including coronary artery and valve disease, congenital heart defects, vascular surgery, drug treatment and diagnostic techniques.

With incentives other than the progression of medicine, the content of journals is often called into questions as studies have surfaced where their findings can be far from conclusive as their findings are source from a single case treatment (Smith, 2006). The journals research must come from *“systematic meta-analysis of multiple studies conducted by different researchers...with negative studies”* (Wicks, 2014, point 22). Coupled with journal access being expensive, the legitimacy questions do call into interest the impact journals may have on quality of health care as well the new dynamic created between doctors and patients as new with the easy access application of WEB 2.0 information which was once restricted for doctors only is now also available for patients (Wicks, 2014).

2.4 IMPACT OF ONLINE MEDICAL INFORMATION

The amount of medical information made available to patients and doctors has definitely increased with the use of WEB 2.0 applications. This in turn has significantly raised the general public's awareness in medicine, creating a *"huge shift from the paternalistic view of medical care in which patients entrust their health to their physicians, whom they visit for an annual checkup or when faced with an injury or illness"* (Shneiderman et al., 2013, p59). Patients are now becoming much more involved in the decision making process of their own health care. This can have both positive and negative impacts. The quality of information online is vital to ensure this shift to a more balanced relationship between patients and doctors and is of benefit to the quality of healthcare. The truth of the matter is that unfortunately *"there is a lot of rubbish on the web – more than in printed books, perhaps because they cost more to produce"* (Brockman, 2011, p10).

With information online being easily accessed and edited, it can be misleading or misinterpreted, which in turn can create serious problems in the behavior of patients whether it may be questioning a physician's authority or requesting an inappropriate treatment (Murray et al., 2013). However one of the most dangerous outcomes is patients' information usage for 'self-diagnosis' leading to overestimating or underestimating a medical issue, both of which can create more problems to the patient (Murray et al., 2013).

Pew Research Center is a nonprofit company which carries out research into new trends and changing attitudes around the world (Fox & Jones, 2009). It developed the Pew Internet Project in an effort to explore the impact of internet on different demographics, with a report carried out between 2002 and 2008 on how the internet has impacted healthcare as a source of information for patients (Fox & Jones, 2009). The report collected its data from a group of 2,253 adults with diverse backgrounds and age groups revealing several interesting insights (Fox & Jones, 2009). When asked which of the following sources of medical information do you use the results showed the following.

Table 9 – Source of Medical Information © Pew Research Center, 2014

WHICH SOURCE DO YOU USE FOR MEDICAL INFORMATION
• 86% of all adults ask a health professional, such as a doctor.
• 68% of all adults ask a friend or family member.
• 57% of all adults use the internet.
• 54% use books or other printed reference material.
• 33% contact their Insurance provider.
• 5% use another source not mentioned in the list.

Table 10 – Impact in General © Pew Research Center, 2014

DID THE ONLINE HEALTH INFORMATION IMPACT THEM
• 13% of e-patients say their recent inquiry had a major impact.
• 44% of e-patients say it had a minor impact.
• 41% of e-patients say their most recent inquiry had no impact.

Table 11 – Impact in Decision Making © Pew Research Center, 2014

HOW DID ONLINE INFORMATION AFFECT YOUR DECISIONS
• 60% say the information found online affected a decision about how to treat an illness or condition.
• 56% say it changed their overall approach to maintaining their health or the health of someone they help take care of.
• 53% say it lead them to ask a doctor new questions, or to get a second opinion from another doctor.
• 49% say it changed the way they think about diet, exercise, or stress management.
• 38% say it affected a decision about whether to see a doctor.
• 38% say it changed the way they cope with a chronic condition or manage pain.

According to Table 9, the 57% who answered that they were affected by what they read online, a follow up question was asked of how it affected decision making with regards to what they had read, table 10 and 11 (Fox & Jones, 2009).

With the growing use of online medical information, patient - doctor communication is more important than ever to ensure patients who inform themselves through WEB 2.0 are advised by physicians on how to manage their health. But even personal consultation between patients and physicians as method for reviewing online content is not enough.

According to UCL's survey, whilst most physicians state that patients bringing in information can be beneficial, or at least harmless on the outcome of the consultation, 38% of physicians in the U.S believe patients who bring information from the internet to consultations can harm time efficiency (Murray et al., 2003). Recent studies have shown that physicians have followed through with inappropriate requests from patients due to information they acquired from the Internet. This has been attributed to *"either for fear [on behalf of the physician] of damaging the physician/patient relationship or because of the negative effect on time efficiency of not doing so"* (Murray et al., 2003, 'Conclusion').

"...patients may believe that physician refusals may be motivated by the need to control costs. Some physicians may have difficulty adjusting to a more-equal role with patients or may experience conflict with more-assertive patients" (Murray et al., 2003, 'Introduction')

By using existing WEB 2.0 networking applications, or through the creation of new platforms designed specifically for discussing healthcare, communication is being used to filter the information online and provide adequate channels for patients who use the WEB as a source of communication to reach experts and professionals.

Although the study shows that information is accessed by patients, those who do go online do not participate in the online debate. With a lack of participation information can become outdated, or even misleading information might be left unchanged which is a risk for people who are new to the web as a source of information (Fox & Jones, 2009).

Table 12 – Health Information Accessed © Pew Research Center, 2014

HEALTH INFORMATION ACCESSED
• 41% of e-patients have read someone else's commentary or experience about health or medical issues on an online news group, website, or blog.
• 24% of e-patients have consulted rankings or reviews online of doctors or other providers.
• 24% of e-patients have consulted rankings online of hospitals or other medical facilities.
• 19% of e-patients have signed up to receive updates about health or medical issues.
• 13% of e-patients have listened to a podcast about health or medical issues.

Table 13 – Health Information Created © Pew Research Center, 2014

HEALTH INFORMATION CREATED
• 6% of e-patients have tagged online content about health or medical issues.
• 6% of e-patients report that they have posted comments, queries, or information about health or medical matters in an online discussion, listserv, or other online group forum.
• 5% of e-patients say they have posted comments about health on a blog.
• 5% of e-patients have posted a review online of a doctor.
• 4% of e-patients have posted a review online of a hospital.
• 4% shared photos, videos or audio files online about health or medical issues.

Consequently, the growing access to medical information online is considered in general a positive impact on the medical awareness of patients, and democratizes the decision making process between physician and patients creating a healthier relationship. Although there is a risk that the online information is misleading, this can be countered with active participation of patients and doctors on this new online platform, achieved through WEB 2.0 communication such as social networks. By encouraging online participation the information can be constantly updated with new findings, debated and filtered by experts ensuring patients and other individuals are easily gaining access to high quality information.

“For health information on the Internet to achieve its potential as a force for equity and patient well-being, actions are required to overcome the digital divide; assist the public in developing searching and appraisal skills; and ensure physicians have adequate communication skills.”

(Murray et al., 2013, Conclusion)

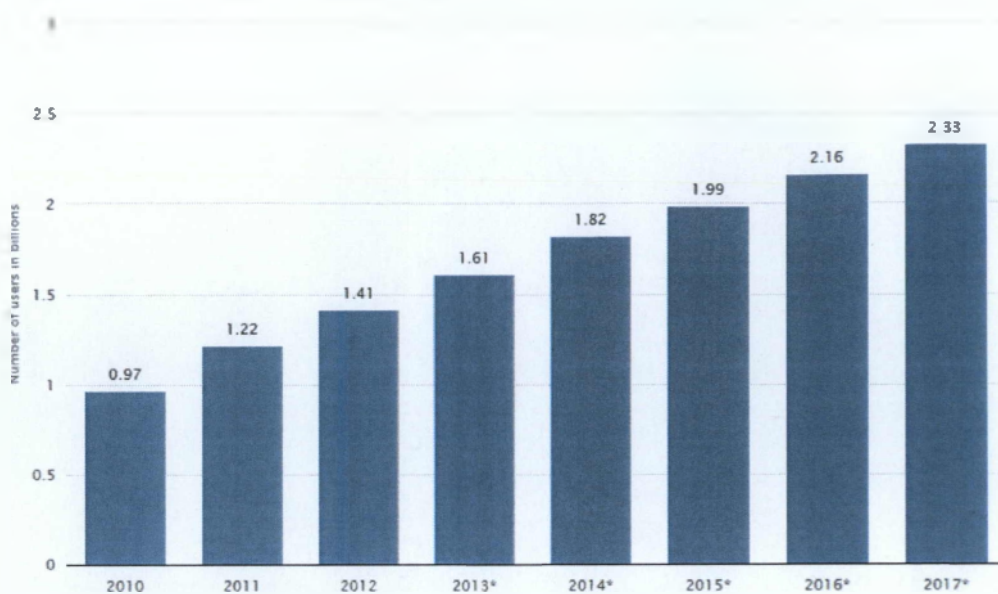
CHAPTER 3: WEB 2.0 AS A COMMUNICATION CHANNEL

3.1 HEALTHCARE AND SOCIAL NETWORKS

Social Networking websites are one of the largest phenomenon of WEB 2.0, introducing technology which facilitates internet communication *“with personal Web pages that permit users to post information about events in their lives, advertise social activities, and share photographs”*(Jain, 2009, para. 3). The leading social network as of 2014 is Facebook, with over 1.2 billion active users, a fact that has attracted ever more mainstream uses by a variety of demographics and professional uses, is no longer being a preoccupation of high-school students (Jain, 2009). With social networks users create an online identity by disclosing their personal information, that varying from phone numbers to sexual orientation and political affiliations (Jain, 2009). Different social networks have varying codes of conduct, however most of them follow a similar model where only certain information can be kept private, or at least be visible to only the people allowed by the account’s user. Most of the information published on social networks however is open to the public and many of these websites have license agreements giving the social network full access to the information uploaded or posted online, which is why internet professionals advocate the use of social networks be done responsibly (Jain, 2009).

Fig. 1 - Social network user statistics © statista.com, 2014

Number of social network users worldwide from 2010 to 2017 (in billions)



Due to the sudden growth of social networks and their intrinsic ability to communicate with a remarkable amount of people around the world instantly, a new environment has been set up for group interacting creating new opportunities and risks for the health care industry (Jain, 2009). For example, a group of physicians called 'Doctors for Obama' takes advantage of WEB 2.0 to communicate with thousands of doctors regarding health policy issues to advise the Obama administration (Jain, 2009). This group of physicians used Facebook during the 2008 presidential campaign to engage with thousands of doctors in order to voice their views of health policy prior to the election (Jain, 2009).

Hospitals are also increasingly using social networks to promote and engage patients and their experiences. Of 5000 hospitals in the US, 700 have a social media profile to enhance their marketing services and communicate with stakeholders (Keckley & Hoffmann, 2010). Other health care centers are developing through websites like Facebook, online communities to engage with patients about their treatment experiences. Other organizations have used social networks to rapidly contact the public in the event of product recalls or too raise awareness over a possible pandemic (Keckley & Hoffmann, 2010).

Similarly to the growing use of social networks by the industry, 60% of surveyed physicians have expressed an interest in the use of social networks for professional purposes, whilst 16% of surveyed physicians are members of Sermo, an online network specifically for physicians (Keckley & Hoffmann, 2010). Sermo is an online social network with over 270,000 active members who are registered physicians from 66 different specialties, which enables users to “collaborate clinically, discuss treatments, solve cases, network, and learn from one another.” (Sermo, 2014, ‘Peter Kirk’). Other online communities such as ‘Diabetes Daily or ‘I Support Cystic Fibrosis research and Awareness,’ promoted through thousands of Facebook members raise awareness and funding as well as doctor patient interaction (Jain, 2009). Despite popularity, the use of social networks in health care is still in its infancy.

“39% of e-patients use a social networking site like MySpace and Facebook and, of those, only a small portion have followed their friends’ personal health experiences or updates, posted their own health-related comments, gotten any health information, or joined a health-related group ... 12% of e-patients use Twitter or another service to share updates about themselves or to see updates about others, and of those, few have posted comments, queries, or information about health or medical matters.” (Fox & Jones, 2009, p3)

The reason why social networking websites have not reached their full potential in the healthcare industry is mainly attributed to concerns regarding privacy issues since “social networks, by definition, facilitate communication among many parties simultaneously” (Hawn, 2009, p363). A patient’s health information is a very fragile matter which should not be shared and discussed online with public access unless the patient feels comfortable within a certain level of confidentiality or anonymity (Hawn, 2009). Health care is definitely adjusting to the growing trend of social networks with websites being developed specifically for healthcare communication, however health care policy must also be adjusted according to this new interactive environment in order to allow for its true potential to be reached. To do so, the issues which may arise from public access and online communication in healthcare must be determined whilst true potential of such systems explored in order to setup online platforms which benefit the healthcare industry as whole but specifically patients.

3.2 THE SHORT FALLS OF SOCIAL NETWORKING IN HEALTHCARE

With the expansion of healthcare services through WEB 2.0 applications certain problems have emerged from using this software as a method of sharing and communicating medical information. Three key issues are addressed when it comes to healthcare in social networks which can be referred to as 'E-professionalism', 'Doctor Patient Relationships' and 'Professional Reputation' (Cain, 2011). It is important for patients, doctors and others within healthcare to understand potential issues of using social networks and act responsibly online.

With more and more people signing up to social networks, there is a new platform which brings patients and healthcare professionals in an environment which might not offer direct contact but can interact in a non-professional context. As an example, if a doctor has "friended" a patient online, the patient will be able to access information from that doctor in a different context, whether personal photos, conversation topics outside of medical practice or even music preference. These information types can change the dynamic between the people within healthcare.

E- PROFESSIONALISM

There are many examples of health care professionals finding themselves liable for inappropriate behavior on social networks posts, where from instance "*a hospital employee [...] 'Tweeted' her opinion that a state governor had received preferential treatment during a checkup. The employee was suspended without pay for violating patient confidentiality, and she ultimately resigned*" (Cain, 2011, p1037).

In the era before WEB 2.0 the private life of a healthcare professional was easily kept separate from the workplace, but with private life expanding into the public environment of social networks, the line is becoming blurred leading to professional making mistakes like in the example above (Cain, 2011). Thus it is crucial for health care professionals to adequately inform themselves of the nature of social networks and maintain a level of professional integrity.

"E-professionalism and online professional boundaries are important constructs for all to understand in order to safeguard their reputations and careers." (Cain, 2011, p1036)

However a lack of appreciation on the implication of social media is not the only problem, as recent studies have shown that some students believe that the “information published via social media is irrelevant to the workplace and should not be used for judgments of professional ability or reputation, regardless of the type of information posted (Cain, 2011). In another study 20% of the confidential and private information of a U.S. company was exposed through social media sites, whilst 21% reported having to discipline an employee for violating social network company policy (Cain, 2011). The importance of informing healthcare professionals of E-professionalism can save not only money but time which otherwise would be lost in lawsuits, fines placing institutions into financial risk (Cain, 2011).

“The federal Privacy Rule was issued by the Department of Health and Human Services to implement a requirement of the Health Insurance Portability and Accountability Act (HIPAA). Per this rule, communications regarding personally identifiable patient information must be secure and transmitted only to permissible parties” (Cain, 2011, p1037)

REPUTATION ISSUES

The outcome of a lack of online professionalism can subsequently lead to compromising the reputation of healthcare professionals, institutions, private companies or other related health care professionals. A hospital, company or even government “often depends on the attitudes, behavior, and work ethic of the individual employees or members—the ‘faces’ of the organization” (Cain, 2011, p1036). Whilst social networks have the ability to facilitate communication within healthcare this advantage can also turn to a disadvantage, as the ability to miscommunicate or share certain private information or opinions can reflect a negative image for an entire organization, especially if the individual involved can be viewed as a representative of that organization (Cain, 2011). Comments, posts and videos posted on websites like Facebook, Twitter or YouTube can be taken out of context intentionally or unintentionally to reflect a false opinion or fact and through the mass communication of social networks set a negative impact for an institution which is then difficult to make right (Cain, 2011).

There was another example of such incident in a recent study on the impact of social media where pharmacists were criticizing online through blogs the work ethic of co-workers stating an absence of empathy toward patients and a lack of respect to the other healthcare professionals (Cain, 2011). In the specific example the blog authors were not disciplined by their employers as they had remained anonymous online, however if it had not been anonymous the employers would have to manage the situation differently in order to distance themselves from an opinion which if made public could damage the business reputation (Cain, 2011).

Recently an email to students circulated the faculty of Harvard Medical School stating *"Caution is recommended . . . in using social networking sites such as Facebook or MySpace. Items that represent unprofessional behavior that are posted by you on such networking sites reflect poorly on you and the medical profession."* (Jain, 2009, para. 5). With social media being a platform which facilitates communication on a global level across all demographics, with doctors and patients both having personal accounts on Facebook, Twitter, LinkedIn etc, and viewing each other's post, photographs and opinions it begs to ask the next question, how will social networks affect the patient-doctor relationship and subsequently impact healthcare? After all, doctors and other healthcare professionals are members of real communities and have a personal life outside of their professional image (Jain, 2009). As social networks can be used for both personal and professional reasons the boundaries become blurred and misunderstandings can emerge.

RELATIONSHIP DYNAMICS

It is constantly being reminded to students during their medical training to maintain a professional distance from their patients, regardless how sympathetic they might feel with them (Jain, 2009). The use of beepers and pagers were a strategy to maintaining such a distance however with the expansion of Facebook-like social networks, maintaining this distance is becoming even more difficult (Jain, 2009). The issue in question is can social media strengthen patient-doctor relationship while maintaining a level of professionalism? Should healthcare professionals accept a patient as a Facebook friend, and if not might rejecting the patient be misunderstood and create tension in the relationship? Most members of

the medical community believe that it is unwise for health care professionals to interact with patients on social media sites, for several reasons but mainly to avoid blurring the line between personal and professional life (Cain, 2011).

"In my second week of medical internship, I received a "friend request" on Facebook, the popular social-networking Web site. The name of the requester was familiar: Erica Baxter. Three years earlier, as a medical student, I had participated in the delivery of Ms. Baxter's baby. Now, apparently, she wanted to be back in touch. Despite certain reservations, I clicked "confirm," and Ms. Baxter joined my list of Facebook "friends." I was curious to hear about the progress of her baby girl, but I wondered about the appropriateness of this interaction. Was Ms. Baxter simply a grateful patient interested in sharing news about her child — as a follow-up to our professional interaction — or did she have other motives that weren't apparent to me? In confirming this patient as my "friend" on Facebook, I was merging my professional and personal lives. From my Facebook page, Ms. Baxter could identify and reach anyone in my network of friends, view an extensive collection of personal photographs, read my personal blog, and review notations that others had left on my "wall." The anxiety I felt about crossing boundaries is an old problem in clinical medicine, but it has taken a different shape as it has migrated to this new medium."(Jain, 2009, para. 1&2)

Any mistake in online behavior that is visible to patients can have lasting effects on reputation, or problems in the work place and follow through into a healthcare professional's personal life (Jain, 2009). In reality the issues raised are very similar to issues that have been dealt with for year, even before the arrival of WEB 2.0, the problem of blending personal and professional life (Jain, 2009). Yet, regardless of all the hesitation, according to surveys only 20% of physicians see online interaction with patients as inappropriate, or view the technology as a potential risk, a number supported by the potential physicians see in WEB 2.0 tools if implemented currently with appropriate policy and software which deals with issues in of privacy, professionalism, reputation and boundaries (Hawn, 2009).

“After becoming my Facebook friend and exchanging a few friendly e-mails, Ms. Baxter divulged the reason she had gotten back in touch. Having tired of her job as a fitness instructor, she had decided to apply to medical school and wanted some advice. Relieved to be back in a semiprofessional realm, I began a correspondence with her and shared a few thoughts and suggestions. Among other things, I recommended that she carefully consider her online identity.” (Jain, 2009, para. 7)

Thus, with their growing popularity social media are consistently being used more and more by business, not only by employees and employers but by their customers as well, interacting with each other in order to improve their service or product (Vikram, 2010). Social networks are impacting public opinion, in such a way which reaches local government and subsequently becoming government policy (Vikram, 2010). Therefore, it is vital for healthcare organizations to understand this new dynamic and the power of social media in order to use this new technology to raise their quality and efficiency (Vikram, 2010)

“Developing a social media policy is no longer an option today, it is a necessity. If healthcare organizations do not take efforts in this direction, they run the risk of becoming stagnant and perhaps obsolete in the long run.” (Vikram, 2010, p8)

By implementing social media policy in health care, the potential of using WEB 2.0 applications can be truly reached, without running the risk of facing the problems discussed above, which are only a few of the many ways WEB 2.0 can create problems rather than resolve them. However, if used responsibly, social networks can become a platform to develop an interactive healthcare medium where communication and trust are key to achieving better quality of healthcare. WEB 2.0 can be used to empower patients, giving them a voice of impact, encouraging the industry center around the needs of patients and not the demands of stakeholders (Hawn, 2009).

TABLE 14 – Required Healthcare Policy in WEB 2.0 © Jeff Cain health-syst pharm, 2011

ISSUE	MAJOR POLICY ELEMENT
REPUTATION	<ul style="list-style-type: none"> - Define who is permitted to speak officially on behalf of the organization through social media. - State that if employees' posts can be linked to the organization, employees should not post anything that is potentially damaging to the organization. - State that when expressing personal opinions on social media, employees should provide a disclaimer advising that they are not speaking officially on behalf of the organization. - State that the organization reserves the right to request removal of any potentially damaging information.
PRIVACY	<ul style="list-style-type: none"> - State that social media postings should not reveal private information about patients. - State that social media postings should not reveal confidential or proprietary business information.
GENERAL	<ul style="list-style-type: none"> - State that all other organization policies (e.g., harassment, ethics) are applicable to social media communications. - State that individuals are personally responsible for all social media posts. - State that employees should not expect privacy on social media. Define consequences for violating policies.

3.3 THE POTENTIAL OF SOCIAL NETWORKS AND HEALTHCARE

It is evident that mainstream social media networks, such as Facebook and Twitter “do not meet the technical criteria for secure communication of patient information in order to discuss patient cases [...] even if it occurs among those who have a legal right to exchange such information in a secure fashion” (Cain, 2011, p1037). However the potential benefits from using Web 2.0 tools in healthcare have drawn enough interest for investment into solving these issues.

“Social networks hold considerable potential value for health care organizations because they can be used to reach stakeholders, aggregate information and leverage collaboration.” (Keckley & Hoffmann 2010, p1)

Towards using WEB 2.0 in healthcare, certain initiatives will be required which in turn must provide an incentive in order to attract investment (Keckley & Hoffmann 2010). As healthcare consumers increasingly use the Internet and social media to search or health information, share personal experience and choose providers, industry stakeholders not only face a challenge of adapting to this new technology, but also stand to profit from it (Keckley & Hoffmann 2010). For example data extracted from Twitter can be used by public health analysts, given it is publicly accessible, as source of information for how medical trends spread (Shneiderman et al., 2013). Network analysis metrics such as ‘Betweenness’, ‘Eigenvector’ and other algorithmic computer software can scan the discussions of active online communities to help detect key influence for each medical topic (Shneiderman et al., 2013). In other words, the expansion of healthcare stakeholders into WEB 2.0 have direct insight into the trends and opinions of healthcare consumers allowing them manage and adapt their services according to patient requirements both making them more efficient. This is of financial benefit to the industry, and fit for consumer needs which is of benefit for patients (Shneiderman et al., 2013). It is important for the industry to comply with regulations and maintain a balance between efficiency and quality.

Beside online patient communities, healthcare industry can also gather and analyze information from online physician communities allowing them reach a wider spectrum of clinicians quickly and effectively either to inform of new treatments or receive feedback (Modalh et al., 2011). WEB 2.0 and specifically social networks can

also provide opportunities for healthcare systems to setup regulated platforms, educate customers about their products, and provide physicians with patient education materials and other tools - perhaps even finding ways to collaborate on things such as solutions adherence (Modalh et al., 2011).

“Importantly, in order for pharmaceutical and med tech companies to use this new media to its full potential, additional regulatory clarity is required” (Modalh et al., 2011, p12)

Perhaps the greatest incentive of using WEB 2.0 in health care is its *“ability to collect and disseminate information quickly and freely among large numbers of people simultaneously”* (Hawn, 2009, p363). The data collected can then provide community summaries and feedback reports for treatments and symptoms (Frost et al., 2008). For example Twitter was used as a method of tracking the development of flu epidemics giving a fast and free method of gathering vital information for healthcare government agency to take appropriate measures to contain the outbreak (Brooke, 2013). The above example could only occur with the existence of Web 2.0 and the current ease of access to mobile hardware such as smartphones and laptops which are no longer expensive tools narrowing *“the communication gap between patients and healthcare providers, as well as between educators and learners (Paton et al., 2010). Healthcare professionals, institutions and patients now have “access to multiple information sources instantaneously influencing all individuals at the global level who have access to the mobile tools.” (Paton et al., 2010, p4). This gives WEB 2.0 in healthcare its ultimate power, “rendering command and control of [healthcare] information far more challenging making it accessible to patients, allowing them to responsibly control their health care decisions [and impact healthcare policy making]”* (Hawn, 2009, p363)

Furthermore, returning to the idea of efficiency, there is recent interest in the idea of monitoring a patient’s health remotely, both lowering healthcare costs and provide healthcare to the more remote areas of planet who do not have access to healthcare (Modalh et al., 2011).

“Imagine if the system allowed you to have access to your doctor online, via Skype, or enabled you to discover your doctor’s opinion on a breaking medical news story. Imagine if you owned your, or your children’s, chart,

as well as charts for people for whom you are the primary health advocate. Imagine asynchronous video chats and responses with your clinician from your desk at work. The possibilities are endless. I think it is time for all of us to harness the brilliance of social tools. Patients' online activity should be celebrated, integrated and prioritized. Let's bring doctors and patients back together again by building the tools we need to form valuable partnerships." (Swanson, 2013, para 8)

These ideas of online medical records, remote consultations, ease of access healthcare information, patient privacy and statistical data are being explored through a range of new health specific social networks and blogs, such as "Patients like me"¹. With websites like these many physicians are describing online healthcare interactivity as *"...an opportunity for better education, increased compliance, and better outcomes"* (Modalh et al., 2011, p7).

¹ <http://www.patientslikeme.com/>

CHAPTER 4: AN INTRODUCTION TO PATIENTS LIKE ME

4.1 INTRODUCTION

With ever growing use of WEB 2.0 software for healthcare purposes, whether for information or communication, certain companies saw an opportunity to create new software specific for healthcare. The issues of privacy and professionalism which rised with the use of mainstream social networks for health care purposes coupled with people using websites and wikis to access medical information. This has led to the creation of a number of online communities and social networks specific to healthcare. Developed either by patients, NGOs, private companies or healthcare providers, these *“online communities are virtual forums where patients can discuss their health concerns and exchange information”* (Wicks, 2010, p3). Evidence for the impact participation in online medical communities may have of health outcomes of individual patients is still limited as these communities are a fairly recent phenomenon (Wicks, 2010). However *“psychological benefits and increased quality of patient-physician interactions have been demonstrated”* (Wicks, 2010 p3).

THE 'PATIENTS LIKE ME' PARADIGM

A website with growing popularity specific for gathering and publishing medical information and facilitating communication within the industry is PatientsLikeMe. In a sentence, PatientsLikeMe is a health information sharing website for patients (Patientslikeme.com, 2014).

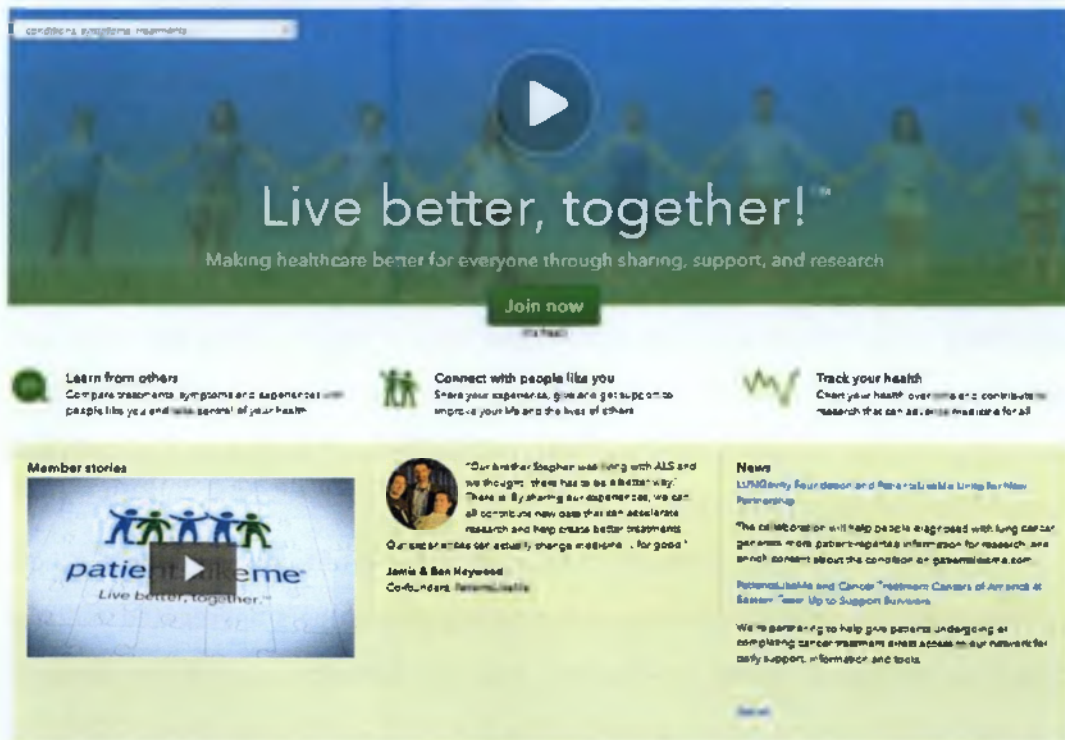
"We're a free patient network where people can connect with each other to better understand their diseases, share condition and treatment information, and get the support they need to improve their health. We're also a real-time research platform. As patients report on their disease experiences, they provide real-world insight into disease. Those insights are shared with companies, government organizations and others who use them to continuously develop more effective products, services and care." (News.patientslikeme.com, 2014)

With more than 300,000 patient members, PatientsLikeMe also functions as a *"clinical research platform that can provide real world, real-time insight into thousands of diseases and conditions"* (Patientslikeme.com, 2014). There is no subscription fee and the website does not follow the traditional form of advertisement revenue such as banners and popups. Its main source of revenue is through the sale of anonymous aggregated data which it collects from its patients input (Brownstein, 2009).

Members of PatientsLikeMe are encouraged to 'share, find and learn' (News.patientslikeme.com, 2014). 'Sharing' involves updating an online profile with all health related information from ones medical history such as the progress of a disease or symptoms to the even the outcome of the prescribed treatment (News.patientslikeme.com, 2014). Members use their online health profiles to chronologically chart the information for monitoring their progress and can choose to share the information with others or even their doctors (News.patientslikeme.com, 2014). 'Finding' refers to website's search engine which allows a member to find which may be dealing with the same medical problems. Through the use of medical profiles, the search can be narrowed down to not only to disease or symptom, but also treatments, geographic location, age and gender (News.patientslikeme.com, 2014). Sharing and finding enable learning, as members

can then communicate through public forums or private messaging discussing their experience with others (Brownstein, 2009). Members can find others which have already had to make decisions they are facing and not only receive advice or support but view the data-driven charts to access the outcome of their fellow patient’s choice (Brownstein, 2009).

“The members of PatientsLikeMe don’t just share their experiences anecdotally; they quantify them, breaking down their symptoms and treatments into hard data. They note what hurts, where and for how long. They list their drugs and dosages and score how well they alleviate their symptoms. All this gets compiled over time, aggregated and crunched into tidy bar graphs and progress curves by the software behind the site. And it’s all open for comparison and analysis. By telling so much, the members of PatientsLikeMe are creating a rich database of disease treatment and patient experience.” (Goetz, 2008)



Fi. 2 - Patients Like Me homepage © PatientsLikeMe.com, 2014

That is why PatientsLikeMe has also recently been “gaining recognition for its clinical research in areas as diverse as patient-reported outcomes, identification and quantification of symptoms in neurological diseases, patient education and decision-making, and patient-lead clinical trials” (Wicks, 2010, p4). However, its main goal remains to help patient members find support and accurate information from other patients or physicians, helping and guiding them to reach the best outcome possible (Wicks, 2010). The information gathered from the clinical research conducted not only help to finance the platform but also provides useful information to improve the quality of healthcare in general (Patientslikeme.com, 2014). The data gathered is sold to companies and institutions, as real time feedback on the outcome of the products sold to patients (Patientslikeme.com, 2014).

“These products may include drugs, devices, equipment, insurance, and medical services. Except for the restricted personal information you entered when registering for the site, you should expect that every piece of information you submit (even if it is not currently displayed) may be shared with our partners and any member of PatientsLikeMe, including other patients. We do not rent, sell or share personally identifiable information for marketing purposes or without explicit consent.”

(PatientsLikeMe help center, 2014)

The websites members, by sharing their information, allow the data to be presented individually as graphical profiles and reports (Wicks, 2010). Members can later choose to share or discuss the data with other members in a group forum or through a private messaging service (Wicks, 2010). They can even print this data and consult their doctor or physician.

PatientsLikeMe describes its practice as a ‘for-profit company, with a not-just-for-profit attitude’, as the reason for selling its members aggregated medical data is a strategy to bring patients and industry interests together in order to improve healthcare and patient quality of life (PatientsLikeMe help center, 2014). As a platform PatientsLikeMe appreciates the capabilities of WEB 2.0 software for communications and sharing information, allowing it to effectively sharing real-world medical issues with the healthcare industry to raise awareness so that organizations and institutions focus on patients’ current needs (Patientslikeme.com, 2014).

TABLE 15 © PatientsLikeMe Privacy Policy, 2014

PATIENTSLIKEME MEMBER INFORMATION	
SHARED DATA	RESTRICTED DATA
Biographical information, e.g. photograph, biography, gender, age, location (city, state and country), general notes;	Name, as collected as part of registration or in a Member's Account Information
Condition/disease information, e.g. diagnosis date, first symptom, family history	Email address, as collected and verified as part of registration or in a Member's Account Information
Treatment information, e.g. treatment start dates, stop dates, dosages, side effects, treatment evaluations	Password, as collected as part of registration or in a Member's Account Information
Symptom information, e.g. severity, duration	Mailing address, as collected via email, forms, or private message as part of
Primary and secondary outcome scores over time, e.g. ALSFRS-R, MSRS, PDRS, FVC, PFRS, Mood Map, Quality of Life, weight, InstantMe	Member programs such as t-shirt giveaways and PatientsLikeMeInMotion
Laboratory results, e.g. CD-4 count, viral load, creatinine	Date of birth, as collected in My Profile
Genetic information, e.g. information on individual genes and/or entire genetic scan	Private messages between members
Individual and aggregated survey responses	
Information shared via free text fields, e.g. the forum, treatment evaluations, surveys, annotations, journals, feeds, adverse event reports; and	
Connections to other people on the Site, e.g. invited care team member, mentors, feeds, subscriptions.	

4.3 'PATIENTS LIKE ME' COMPANY HISTORY

Brother's Benjamin and Jamie Heywood alongside their family friend Jeff Cole where inspired to improve their brother's life, Stephen Heywood who in 1999 was diagnosed with Lou Gehrig' disease at age of 29. The three MIT engineers *"conceptualized and built a health data-sharing platform that [they] believe [could] transform the way patients manage their own conditions [and] change the way [the] industry conducts research and improve patient care"* (Patientslikeme.com, 2014).

"We started in 2005 by building a strong ALS/MND community (and extended that to include Primary Lateral Sclerosis (PLS) and Progressive Muscular Atrophy (PMA). Over the course of six years, we expanded the site to include communities for Parkinson's disease, Multiple Sclerosis, HIV/AIDS, Mood conditions (including depression, anxiety, bi-polar, obsessive-compulsive disorder and post-traumatic stress disorder), Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Devic's Neuromyelitis Optica (NMO), Fibromyalgia/Chronic Fatigue/ME, Epilepsy, and Organ Transplants."

(PatientsLikeMe help center, 2014)

Jamie, the eldest of the brothers, quit his job to setup a nonprofit ALS therapy development institute hoping to find a cure for his brother who had been diagnosed with ALS (Arnst, 2008). As a nonprofit company the progress was slow, so in 2004 he recruited his brother Benjamin and friend Jeff Cole to set up a private company hoping that it would speed up the process (Arnst, 2008). The three appreciated the potential of healthcare in WEB 2.0 so they setup a forum, using similar software to that of online dating websites, which allowed ALS patients to communicate and discuss treatments together (Arnst, 2008).

Investors were hard to find, but they managed to pull enough funding together from, around "\$750,000 in combined seed money from CommerceNet, an e-commerce incubator, and from eBay founder Pierre M. Omidyar's investment group" (Arnst, 2008). In 2006 the PatientsLikeMe website saw its first BETA Launch in March, however in November of that year the company founders' brother Stephen unfortunately lost his life when his ventilator accidentally disconnected, a not-

uncommon danger according to Jamie, who stated *“I think if PatientsLikeMe was around earlier, it wouldn’t have happened, [...] because other patients would have put Stephen on guard”* (Arnst, 2008, para. 19).

By 2007 the company had raised \$5 million from venture capital firms bringing it closer to its goal of creating a large and diverse “community of patients, doctors, and organizations that inspires, informs, and empowers individuals” (News.patientslikeme.com, 2014). Today PatientsLikeMe has four key investor, with the first being CommerceNet who *“provided the seed capital, guidance, additional management experience, and key connections to help kick start PatientsLikeMe CommerceNet provided the seed capital, guidance”* (Patientslikeme.com, 2014). The second key investor is Omidyar Network an *“investment group committed to fostering individual self-empowerment on a global scale”* (Patientslikeme.com, 2014). The other two investors are Collaborative Seed and Growth Partners, who is an investment company interest in early-stage technology, and Invus Group, which is *“New York-based investment firm with over \$4B of capital in an evergreen structure”* (Patientslikeme.com, 2014).

PatientsLikeMe has expanded in members, partners, technology and revenue return. Its most notable achievements in Business, Research and Patients Support are outlined in the company’s website and seen in the following tables.

“At PatientsLikeMe, we are passionate about bringing people together for a greater purpose: speeding up the pace of research and fixing a broken healthcare system.” (Blog.patientslikeme.com, 2014)

TABLE 16 - Patient Support Milestones © PatientsLikeMe Milestones, 2014

PATIENT SUPPORT MILESTONES	
2008	<ul style="list-style-type: none"> • PatientsLikeMe introduces a new community for people with mood conditions (announced and featured in the <i>New York Magazine</i> article "Practicing Patients" by Thomas Goetz) • The company conducts its first-ever study on Young-Onset Parkinson's disease (YOPD) patients and finds they suffer greatly from non-motor symptoms • In March, PatientsLikeMe launches its next community for patients with HIV/AIDS including CD4 and viral load tracking • The company also launches first of its rare neurological disease communities - neuromyelitis optica (NMO), progressive supranuclear palsy (PSP) and multiple system atrophy (MSA)
2009	<ul style="list-style-type: none"> • PatientsLikeMe launches new communities for Fibromyalgia and chronic fatigue syndrome (CFS) patients • PatientsLikeMe research team develops the ALSFRS-EX to help record the function of severely patients with severe ALS to record their function • PatientsLikeMe launches new features for patients with rare ALS subtypes: primary lateral sclerosis (PLS) and progressive muscular atrophy (PMA)
2010	<ul style="list-style-type: none"> • The company collaborates with Novartis to connect patients with organ transplants to learn about their challenges and solutions • PatientsLikeMe partners with UCB to enable patients with epilepsy to record their seizures and learn from one another
2011	<ul style="list-style-type: none"> • PatientsLikeMe partners with the nonprofit R.A.R.E Project (Global Genes) with the goal of finding and connecting 1 million rare disease patients • PatientsLikeMe opens to all conditions; grows from 12 communities to 1,200 in just 12 months • In <i>Nature Biotechnology</i> publication, PatientsLikeMe refutes 2008 PNAS paper on the efficacy of lithium carbonate on ALS; marks 1st time a peer-to-peer network used to evaluate a treatment in real time and refute clinical trial
2012	<ul style="list-style-type: none"> • PatientsLikeMe teams with TED Fellow Dr. Max Little to advance Parkinson's research through his Parkinson's Voice Initiative • PatientsLikeMe's MS and Fibromyalgia communities reach 30,000+ patients each • The number of diseases and conditions grows to 1,500+ being shared on PatientsLikeMe • PatientsLikeMe begins a new collaboration with Merck focused on understanding psoriasis
2013	<ul style="list-style-type: none"> • Members contribute patient-reported data on more than 2,000 conditions, including 1 million symptom and treatment reports • PatientsLikeMe's fibromyalgia community grows to include 41,000 members; the MS community reaches 33,000 members • In conjunction with The AKU Society, PatientsLikeMe develops the world's first open registry for Alkaptonuria patients • PatientsLikeMe research team studies weekly fluctuations in Parkinson's patients and finds the disease more variable than once thought • PatientsLikeMe's idiopathic pulmonary fibrosis (IPF) community reaches 1,500, making it one of the largest and most active IPF online patient networks.
2014	<ul style="list-style-type: none"> • More than 250,000 patients are now on PatientsLikeMe

TABLE 17 - Business Milestones © PatientsLikeMe Milestones, 2014

BUSINESS MILESTONES	
2004	<ul style="list-style-type: none"> Inspired by the life experiences of Stephen Heywood, PatientsLikeMe is founded by his brothers Jamie and Ben Heywood and long-time family friend Jeff Cole
2006	<ul style="list-style-type: none"> In the Spring, the company launches its website, PatientsLikeMe.com In November, Stephen Heywood, the inspiration for PatientsLikeMe, passes away
2009	<ul style="list-style-type: none"> The company teams with 23andMe to help understand the genesis of Parkinson's Disease Co-founder Jamie Heywood testifies before the National Committee for Vital and Health Statistics on the future of e-healthcare and patients-centric healthcare
2010	<ul style="list-style-type: none"> Co-founder Jamie Heywood shares his vision on the future of medicine at TEDMED R&D Director Paul Wicks talks about making "molehills out of mountains" with data at TEDx Berkshires
2011	<ul style="list-style-type: none"> Co-founder Ben Heywood presents at TEDx Cambridge on "Thriving Against Expectations" PatientsLikeMe opens its website to people with any condition; evolves from 12 disease communities to one community with 1,200 diseases in first year The company launches a new clinical trial matching feature that integrates with ClinicalTrials.gov and helps members identify relevant trials The PatientsLikeMe research team develops tool to help MS patients identify barriers to properly taking their medication; licenses it for free research use
2012	<ul style="list-style-type: none"> To date, PatientsLikeMe has now worked with 20+ pharmaceutical companies worldwide Our team has now testified before or presented to the following government organizations: <ul style="list-style-type: none"> Institute of Medicine Centers for Disease Control & Prevention National Biosurveillance Advisory Subcommittee U.S. Department of Health and Human Services U.S. Food and Drug Administration National Institute of Health
2013	<ul style="list-style-type: none"> Martin Coulter is named as PatientsLikeMe's first CEO PatientsLikeMe unveils new tool to match patients with clinical trials worldwide Robert Wood Johnson Foundation awards PatientsLikeMe a \$1.9 million grant to create a real-time health learning system for the development of patient-centered health outcome measures. The award is announced by R&D Director Paul Wicks live on stage at TED. PatientsLikeMe and Boehringer Ingelheim establish a health information collaboration for patients with idiopathic pulmonary fibrosis PatientsLikeMe builds out the next generation patient registry, a dynamic and collaborative environment to advance medicine
2014	<ul style="list-style-type: none"> More than 250,000 patients are now on PatientsLikeMe

TABLE 18 - Research Milestones © PatientsLikeMe Milestones, 2014

RESEARCH MILESTONES	
2004	<ul style="list-style-type: none"> • PatientsLikeMe publishes novel study indicating that excessive yawning is common in certain forms of ALS • PatientsLikeMe is named British Neuropsychiatry Association Scientific poster winner
2008	<ul style="list-style-type: none"> • PatientsLikeMe identifies higher rate of non-motor symptoms among young onset patients with Parkinson's disease, announces findings at YOPD Conference
2009	<ul style="list-style-type: none"> • <i>Nature Biotechnology</i> reports advances on the PatientsLikeMe site including the ability to identify the potential for off-label uses of existing drugs
2010	<ul style="list-style-type: none"> • In <i>Journal of Medical Internet Research</i>, PatientsLikeMe publishes results of user survey suggesting that members perceive a variety of benefits from using the site, including feeling better informed about their treatment decisions, better communication with their healthcare providers, and improved quality of life
2011	<ul style="list-style-type: none"> • In <i>Nature Biotechnology</i> paper, PatientsLikeMe refutes 2008 PNAS paper on the efficacy of lithium carbonate on ALS; marks 1st time a peer-to-peer network used to evaluate a treatment in real time and refute clinical trial • PatientsLikeMe launches new feature for patients to accelerate clinical trial enrollment with data from ClinicalTrials.gov • In <i>Amyotrophic Lateral Sclerosis</i>, PatientsLikeMe and Charite validate the ALS Functional Rating Scale (ALS-FRS) for web use • Award-winning study on patient-reported outcomes published in <i>Journal of Medical Internet Research</i> • PatientsLikeMe adds new health outcome measures (DLQI in psoriasis and ATEC in autism) so members/caregivers have easier way to do self-assessment and validating PROs
2012	<ul style="list-style-type: none"> • PatientsLikeMe posts patient-reported data on four ALS treatments in trial on figshare.com • PatientsLikeMe research team publishes paper in <i>JMIR</i> about the short-term dynamics of the Parkinson's Disease Rating Scale (PDRS), Mining Online Social Network Data for Biomedical Research • PatientsLikeMe research team reports the first "dose effect curve for friendship" in <i>Epilepsy and Behavior</i>; demonstrates epilepsy patients who connect on PatientsLikeMe have better outcomes • PatientsLikeMe becomes clinically robust resource with 25+ peer-reviewed research studies, earns 300 citations and 1,500 mentions in the scientific
2013	<ul style="list-style-type: none"> • PatientsLikeMe has now published more than 35 research studies • A PROSPER consortium member, PatientsLikeMe works to improve safety reporting in all phases of drug development with patient-reported outcomes of adverse events • PatientsLikeMe selects four pilot researchers for the Open Research Exchange • A sleep survey among 5,256 PatientsLikeMe members reveals that compared to the general population, people living with chronic conditions are nine times more likely to be at risk of having insomnia, and that one of three respondents rarely or never get a good night's sleep • Robert Wood Johnson Foundation awards PatientsLikeMe a \$1.9 million grant to create a real-time health learning system for the development of patient-centered health outcome measures. The award is announced by R&D Director Paul Wicks live on stage at TED

4.3 HOW 'PATIENTSLIKEME' WORKS

Todd Small was stuck in quicksand again. It happened, as always, on the floor of the Seattle machine shop where he worked. His shift complete, Small was making the 150-yard walk from his workstation to his car, when he realized that his left leg was sinking deep in the stuff. Though this had happened before — it happened nearly every day now — he stopped and glanced down at his feet. His Nikes looked normal, still firmly planted on the shop's concrete floor. But he was stuck, just the same. His brain was sending an electrical pulse saying "walk," but as the signal streaked from his cerebellum and down his spinal cord, it snagged on scar tissue where the myelin layer insulating his nerve fibers had broken down. The message wasn't getting to his hip flexors or his hamstrings or his left foot. That connection had been severed by his multiple sclerosis. And once again, Small was left with the feeling that, as he described it, "I'm up to my waist in quicksand."

For the 400,000 Americans with multiple sclerosis, Todd Small's description will most likely ring true. Muscle stiffness is a hallmark of the disease, and "foot drop" — the term for Small's quicksand feeling — is a frequent complaint. The condition is usually treated, as it was in Small's case, with baclofen, a muscle relaxant that works directly on the spinal cord. Every day for 14 years, he took a single 10-milligram pill. "My neurologist always told me if you take too much it will weaken your muscles. So I never wanted to go over 10 milligrams." It didn't seem to have much effect, but he carried on as best he could.

Small would have continued just as he was had he not logged on last June to a Web site called PatientsLikeMe. He expected the sort of online community he'd tried and abandoned several times before — one abundant in sympathy and stories but thin on practical information. But he found something altogether different: data.

After choosing a user name and filling out a profile, Small was asked to list his symptoms and treatments. He entered the 200 milligrams of Provigil he takes daily to fight fatigue along with the Tysabri injection he takes to slow the progress of his disease. And then he clicked on baclofen, and the Web site informed him that nearly 200 patients registered at PatientsLikeMe were taking the drug. He clicked again, and up popped a bold bar graph, sectoring those 200 across a spectrum of dosages. And there it was. Contrary to what his neurologist told him years ago, 10 milligrams 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," Small recalls. "So it hits me: I'm not taking nearly enough of this drug." 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 - there are no miracles in M.S. - but he has found that after 14 years, he can walk to his car without sinking into quicksand. "Oh, man, I really dreaded that walk," Small recalled when I spoke with him recently. "All shift, it'd be in the back of my mind. Am I going to have trouble? Is it going to get me? Now I almost got it figured it out. I don't struggle like I used to."

By THOMAS GOETZ, NEW YORK TIMES Published: March 23, 2008

PatientsLikeMe functions primarily as a social network between patients to effectively share medical information with one another, and even suggest treatments to one other based on personal results and real life data (Singer, 2010). This leads to a line of communication between patients without having to go through traditional channels, such doctors, or without having to share information in online public communities such as mainstream social networks (Singer, 2010). With over 300,000 members and more than 2000 conditions, members can find patients of the similar age, sex, and medical history dealing with the same health conditions and gain advice or discuss their experiences (Patientslikeme.com, 2014). Through its practice the company promotes the idea of the “e-patient, a health consumer empowered by online information gathering” (Singer, 2010).

“What we have done is made a system that allows you to think about personalized medicine” - Ben Heywood Co-Founder, President

(Singer, 2010, para. 8)

PROFILE CREATION

A member creates an online profile with a secure password, and can begin accessing other members' health data. Then, he can also begin uploading information about his own health, from the patient's genetic background, medical history, medical test results, a doctor's diagnosis and all observed symptoms (Brownstein, 2009). The website regularly circulates questionnaires to its members to keep their profile up to date (Upbin, 2013). The website can then analyze this information and present it in charts and graphs so that the patient can easily track and monitor not only his own health but the health of other members in comparison (Brownstein, 2009). With this information, the members-patients can then engage with other members either through specific forums or private messaging to discuss health outcomes in a data driven context (Brownstein, 2009). Patients, who have shared their data and have faced successful treatment or improved their quality of life, take the role of 'expert patients' as they have already been through the decision making process and can offer advice to other patients who are currently having to make big health decisions (Brownstein, 2009). In this discussion members can rate and evaluate treatments and medications, thus using real world experiences to

compare health outcomes from patient testimonies with those reported by clinical trials, making it possible for patients like me to detect “a drug or treatment problems that have not shown up in trials.” (Brownstein, 2009).

Besides the patient search tool, forums, and treatment/symptoms statistics, a members also has a constant news feed keeping him up to date about new research results, patient’s outcomes, or other information directly relevant to the health profile he or she has created. Thus a members profile becomes a detailed day to day report in an effort to measure health progress or viable treatments not just between each medical examinations or consultations, which can last for weeks, but, as part of his or her daily routine.



Fig. 3 - Stephen Heywood profile on PatientsLikeMe. Besides their medical information members can share shoots, personal details and small biographies.

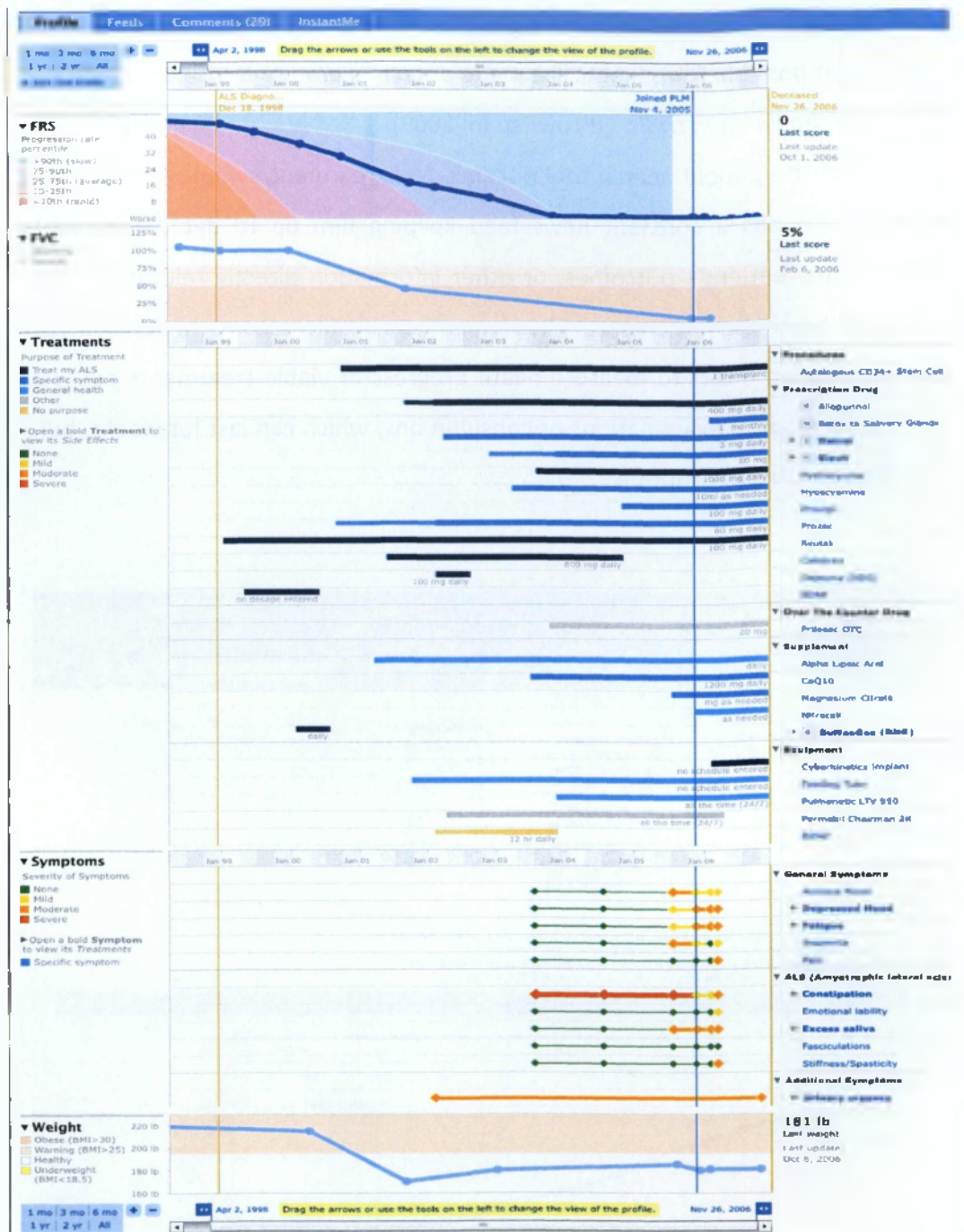


Fig 4. Example of member's profile once it is populated with enough data to create graphical representations of their health status from treatment results, to symptoms, down to weight. The above belonged to Stephen Heywood who suffered from ALS.

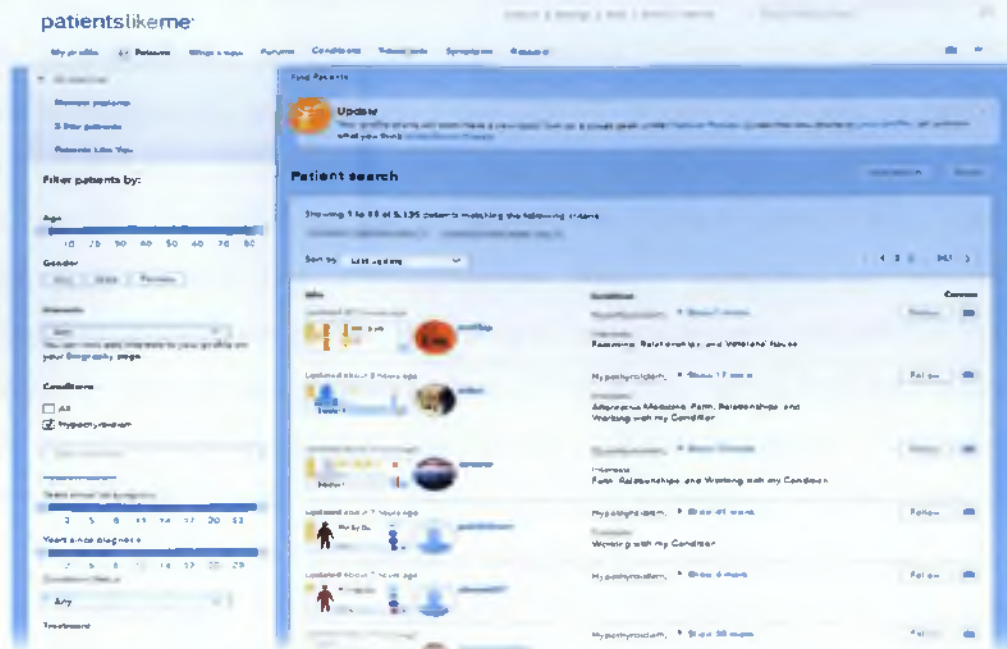


Fig 5. The patient search tool allows members to find other patients with similar health conditions filtered down to age, gender, interests, year since first symptom, year since first diagnosis, treatment etc. The member can then choose to follow the patients profile or even contact him/her directly.

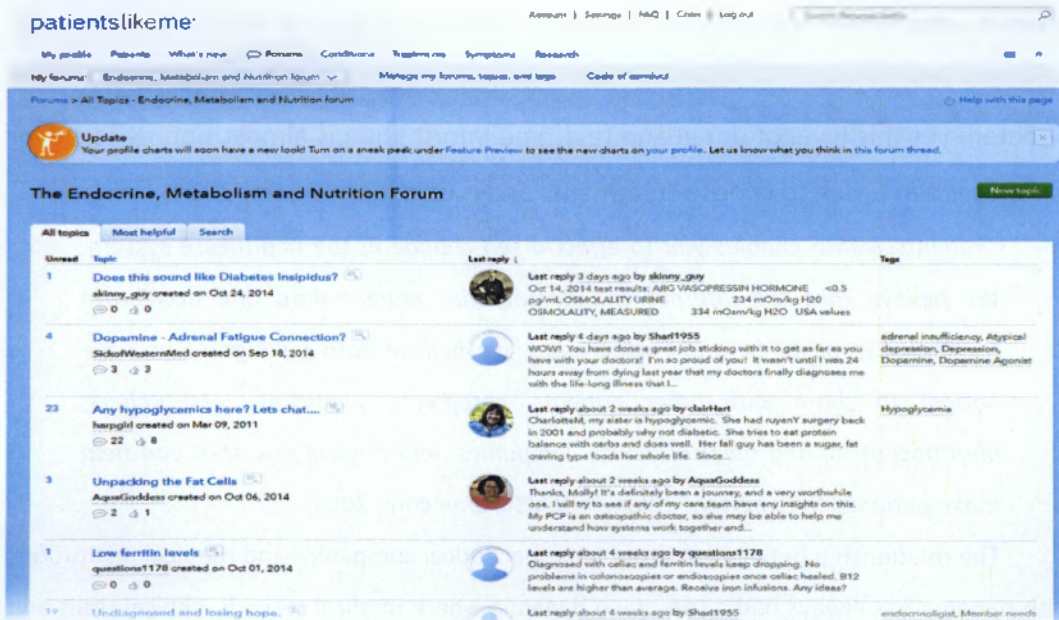


Fig 6. The forum page is a list of relevant forums based on the health conditions posted on a member's profile. Here members can ask questions, share advice and experiences from communities as a whole or simply follow and learn through group discussions.

However PatientsLikeMe is much more than just a chat tool or health specific social network. At the core of PatientsLikeMe, and its source of funding, is the collection of data. Every day on PatientsLikeMe members are collecting, grouping and charting their medical history to great detail (Singer, 2010). This information whether individually charted or grouped in communities is valuable to pharmaceutical companies, medical technology firms and insurance agencies. PatientsLikeMe sells this information, with its member's consent, to its corporate clients and partners as they gain access to *"a rich vein of data on a variety of chronic illnesses that is simply not available anywhere else [and] in return, patients get the hope that they are furthering progress toward cures."* (Arnst, 2008, para. 4). Conversations and profile data are broken down by age, sex, disease progression and treatments, allowing companies to find out not only what is being said about their brand, but also by whom (SINGER 2010). Clinical trials cost billions to government, academia and the pharmaceutical industry and whilst its inherent value may be worth even more, *"this data remains unstructured, unsearchable, incomparable, and hidden from view"* (Wicks, 2014, point 24). It is ironic how as consumers we are offered services and tools through WEB 2.0 applications such as Amazon to instantly compare products online based on real customer experiences at extraordinary levels of detail yet this level of detail and real-time information is almost non-existent for patients when trying to choose treatments and medication (Wicks, 2014).

"PatientsLikeMe enables you to effect a sea change in the healthcare system. We believe that the Internet can democratize patient data and accelerate research like never before. Furthermore, we believe data belongs to you the patient to share with other patients, caregivers, physicians, researchers, pharmaceutical and medical device companies, and anyone else that can help make patients' lives better." (Blog.patientslikeme.com, 2014)

The relationship between doctors, pharmaceutical companies and medical institutions with patients has always had a top-down dynamic where medical records, clinical trials and research papers have been kept away from patients in order to protect privacy (Arnst, 2008). The 'E-patient' model associated with health 2.0 and PatientsLikeMe builds on a belief that information from crowds of patients will shed new insight into areas of medicine which might not receive enough attention and spark funding into developing new treatments (Patientslikeme.com, 2014). This shift towards a new dynamic in medicine

where patients are seen as partners rather than consumers, or statistics, allows patients to impact healthcare outcomes by becoming part of the data used to establish treatment methods and research. The initial impression may seem to be that transparency and patient-to-patient communication may have beneficial effects on healthcare *as “the complexity and novelty of these data coupled with the lack of research in this area means the utility of personal health information for the primary stakeholders -the patients- is not well documented or understood”* (Frost et al., 2008). The benefits and shortcomings of health WEB 2.0 must be accessed in order to appreciate the impact that websites such as PatientsLikeMe will have on healthcare.

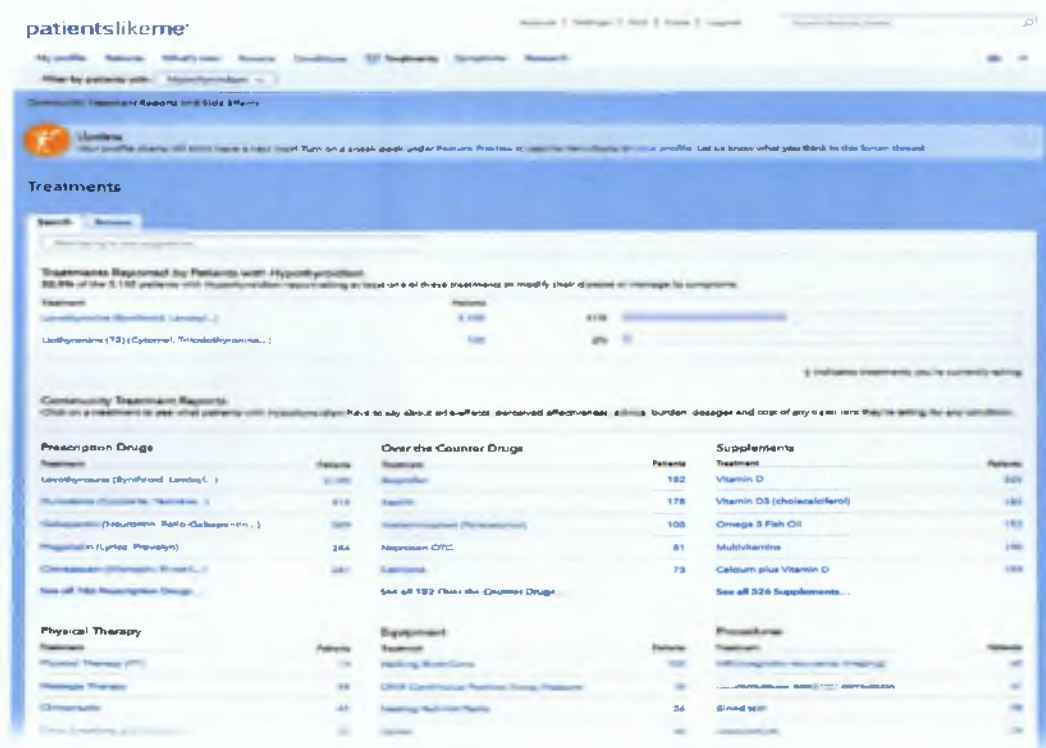


Fig 7. The treatment page allows members to review suggested and patient evaluated treatments for conditions or symptoms. The reviews are substantiated by graphical representations from data collected from user profiles.

CHAPTER 5: THE IMPACT OF PATIENTS LIKE ME

5.1 EMPOWERING PATIENTS OR BREACH OF PRIVACY

The impact of using personal health information by patients is a subject already examined by a few studies (Frost et al., 2008). A study published by the Journal of Medical Internet Research examined the comments and dialogues of PatientsLikeMe website members to determine whether tools which allow patients to share explicit health data are of benefit within a community (Frost et al., 2008). The study revealed that for individuals who choose to share their medical information disease, self-management became easier as health information is structured clearly based on real data. The individuals were also attracted by the ability to find other patients who matched both demographically and medically the receive advice or reassurance with regards to a treatment or symptom (Frost et al., 2008). Unfortunately most health care data, whether derived from clinical trials or journal studies are difficult to find or sometimes even inaccessible due to privacy regulations, proprietary tactics or expensive journal subscriptions (Wicks, 2014). Even the language barrier of a journal makes it difficult for a patient to appropriately interpret the journals findings. PatientsLikeMe and relevant websites “have

demonstrated that with the right information visualizations, explanation, and importantly, the support of their peers, patients with no formal medical training can easily understand many of the important aspects of clinical data” (Wicks, 2014, point 23). This creates a significant question upon the current healthcare system as this information is kept out of reach for the people who have to maintain and deal with a chronic disease (Wicks, 2014).

The idea of sharing information is not just about patient knowledge but advocates the notion of ‘shared decision making’. If patients are appropriately educated and informed of their disease (risks, benefits, alternatives, side-effects of each option), then they can participate in decision making process with their physician empowering them without dismissing the physicians expertise (Wicks, 2014). It allows the patient to understand the physicians and can increase his trust in the physician’s decisions (Wicks, 2014). If patients are unaware of health progress and rely upon each visit to their doctor to receive any feedback from a medical treatment then the patient is rendered powerless, as *“99.9% of our time spent not in the clinic, just living alone with our ailments [...] how do we measure our progress in the in-between time? How do we measure our distance from health?”* (Upbin, 2013, para. 1). In nowadays, patient empowerment, or responsibility, is ever more necessary, as we are witnessing a reduction of infectious diseases in developed nations due to developments in modern medicine and increase in personal and public hygiene, and an increase in chronic conditions such as diabetes, high cholesterol, obesity, and heart disease (Goetz, 2008). These conditions demand years of supervisions and control to eliminate the chances of causing more serious health conditions. PatientsLikeMe provides the necessary tools to monitor chronic diseases and also create support groups where patients can advise and alarm others if they are reveal risk full characteristics. Patients must be aware and educated but also have the tools to monitor and supervisor their health (Goetz, 2008).

In a recent study published in the Journal of Medical Internet Research, a 1323 PatientsLikeMe members responded to a set of questions which aimed “to describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes” (Wicks 2010). The outcomes are shown in table 19.

TABLE 19 - Sharing Health Data for Better Outcomes on PatientsLikeMe © *Journal of Medical Internet Research, 2010*

SHARING HEALTH DATA FOR BETTER OUTCOMES	
TOTAL RESPONSES	1323
PATIENTS WERE ALREADY DIAGNOSED WHEN JOINED	94%
NO CHANGE IN CONFIDENCE OF INITIAL DIAGNOSIS	62%
INCREASED LEVEL OF CONFIDENCE OF INITIAL DIAGNOSIS	34%
BENEFICIAL THE LEARNING ABOUT SYMPTOMS	72%
HELPFUL FOR UNDERSTANDING SIDE EFFECTS	57%
LEARNING FROM OTHER PATIENTS ABOUT TREATMENTS	42%
PROMPTED DECISIONS TO START MEDICATION	37%
PROMPTED DECISION THE CHANGE MEDICATION	27%
PROMPTED DECISION TO CHANGE DOSAGE	25%
PROMPTED DECISION TO STOP MEDICATION	22%
CHANGED PHYSICIAN AS A RESULT TO USING THE WEBSITE	12%
HIV PATIENTS REDUCED RISKY BEHAVIOR	41%
LESS IMPATIENT CARE FOR MOOD DISORDER PATIENTS	22%

While patients may feel empowered by websites such as PatientsLikeMe, because of their ability to quantify and understand the everyday decision they make about their health, there is also a commercial operation behind these tools which sell patients' data to private companies that might not prioritize the same goals as patients (Aldhous, 2008). Moreover, PatientsLikeMe is not covered by US federal regulation intended to protect personal health information (Aldhous, 2008). PatientsLikeMe has a membership disclaimer upon registration of its members' uploaded information and profile data will be sold commercially and visible to others. The fact that patients agree to these terms has surprised the medical community (Arnst, 2008). Medical experts advocate that regardless if participants state they do not care who has access to their medical data, or how public it may be, "there is always the risk that patients will be harmed when personal information is exposed [...] discrimination in health care, housing, and employment is a fact of life" (Arnst, 2008).

Pharmaceutical companies, universities and research labs are among the vast clientele PatientsLikeMe has for selling the data it collects (Arnst, 2008). The company turns a profit from this transaction, which on the one hand maintains the tools which are used for the education and improvement of its member's lives, but on the other could lead to a violation of privacy or exploitation of its members (Arnst, 2008).

"Do we need to protect people who have illnesses from being exploited?" says Cathy Dwyer, an associate professor at Pace University who has studied how advertisers market to consumers based on their online behavior. "It's a very tricky line because people absolutely need emotional support when they are dealing with illness."(Singer, 2010, para. 11)

Unlike television, where consumers can spot pharmaceutical commercials and advertisement, online and especially in patient forums, members may not fully be aware if they are subject to marketing or marketing research (Singer, 2010). A pharmaceutical company could create an account to give false testimonials about a certain product or use patient data to target specific kinds of consumers taking advantage of their vulnerability when looking for online help. This becomes a breach of privacy which is not covered by online privacy policy. In other words, the lack of privacy can leave a patient vulnerable to targeted marketing strategies (Singer, 2010). Whilst most people could share their information for their own benefit or the greater good, there is no safe guard *"knowing whether their health profiles contribute directly to the development of more effective treatments or are simply mined to create more effective drug marketing."* (Singer, 2010, para. 10)

"We are talking about a digital pharma stealth economy that is emerging," says Jeff Chester, the director of the Center for Digital Democracy, a nonprofit group that works to safeguard user privacy. 'You don't know who is being paid to moderate. You don't know who's listening in to your conversation. You don't know what exactly they are focused on and what they are doing with the information."

(Singer, 2010, para. 15)

PatientsLikeMe's privacy policy does not hide these risks, and acknowledges that anybody can register and access profiles (Goetz, 2008). It states no guarantees that registered members are who they say they are. It is actually surprising how vocal the company is about its openness, and rather than trying to dismiss the issue of privacy it concentrates on the benefits, arguing that the benefits of openness outweighs the risks (Goetz, 2008). It means that by sacrificing privacy, research can progress faster by empowering collaboration between patients and researchers. This is a task difficult to achieve due to *"the Health Insurance Portability and Accountability Act of 1996 [HIPAA], which strictly limits the flow of patient records to insurers, employers, and other third parties"* (Arnst, 2008, para. 23). In 1996, and later through a modification in 2002, the government of the United States of America tried to ensure patient privacy by limiting the ability to access electronic records. The law has a list of 18 criteria which a medical record must be stripped of in order to be used by researchers without the patient's consent.

HIPAA however has only received criticism, by both privacy advocates, who are not satisfied by the amount of restriction demanding there be no electronic medical records, and medical researchers, who face restriction to their work slowing down the pace at which they can access information (Goetz, 2008). Alan Westin is a political scientist at Columbia University specializing in privacy legislation. Westin's research identified that 25% of Americans felt that privacy is an valuable right and that no one, either corporate or government, should have access to personal data without permission, whilst on the other end 15% of Americans felt as they had nothing to hide that privacy was dispensable (Goetz, 2008). What Westin identified was that there was a majority of 60% that he labelled as 'privacy pragmatists', who would offer private information to a trusted third party if it was of benefit.

"I know it sounds like really personal information, but it's not like I'm putting my phone number up," says Jennifer Jodoin, [...] who has changed her [Multiple Sclerosis] medications based on information gleaned at PatientsLikeMe. 'I'm not posting my address and saying, 'Come on by.' It's an exchange of information to get help and to give help."

(Goetz, 2008, para. 35)

TABLE 20 - HIPAA PHI: List of 18 Identifiers © UC Berkeley

LIST OF 18 IDENTIFIERS

1. Names
2. All geographical subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code
3. All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death
4. Phone numbers
5. Fax numbers
6. Electronic mail addresses
7. Social Security numbers
8. Medical record numbers
9. Health plan beneficiary numbers
10. Account numbers
11. Certificate/license number
12. Vehicle identifiers and serial numbers, including license plate numbers
13. Device identifiers and serial numbers
14. Web Universal Resource Locators (URLs)
15. Internet Protocol (IP) address numbers
16. Biometric identifiers, including finger and voice prints
17. Full face photographic images and any comparable image
18. Any other unique identifying number, characteristic, or code

Jennifer Jodoin is testament to how people may wish to share their information if this would allow them to steer the direction of research. Through WEB 2.0 software, private medical information of patients gains value as it can be quantified into statistics that can impact the direction and progression of medical research (Goetz, 2008). By converting medical history in manageable statistics the patient can become a stakeholder and have an impact on his healthcare system.

Sharing such information is not something new when it comes to privacy policy. In the past, people have taken blood test to get life insurance, or have consented to share their medical history in a job interview (Goetz, 2008). This is how PatientsLikeMe works around the law, patient consent through a technological loophole. PatientsLikeMe is not a health-care provider so that it may be impacted by

the law (Goetz, 2008). HIPAA's legal reach does not cover PatientsLikeMe as at the time it was passed 1996, or updated in 2002, WEB 2.0 technology was non-existent (Goetz, 2008). Not only do members of PatientsLikeMe volunteer information from the above categories, but they choose to post even more personal information such as personal photos, family photos *"brief autobiographies, [descriptions of] their conditions in precise detail, including potentially embarrassing particulars on sexual function, bladder control or constipation"* (Goetz, 2008). Simply put, HIPAA cannot silence or restrain patients themselves from sharing information, which creates the regulatory loophole for PatientsLikeMe (Goetz, 2008, para. 32).

In order to gain its members confidence to participate, PatientsLikeMe advocates in their 'Data for Good' research program that their corporate or government clients, who buy patient data, create an opportunity not for pharmaceutical companies to market their products but for patients to share their opinions with corporations. This creates a direct line of communication between patients and corporations which in the past was obstructed by physicians or governments. Patients can now have ability and responsibility to voice their own concerns or praise. As Jamie Heywood says, *"Our objective is to teach the company [...] not teach the patient about the company's products."* (Singer, 2010, para. 25).

The debate among privacy and patient empowerment does seem to favor patient empowerment, as privacy concerns do not outweigh the benefits of patients become informed and responsible for their health, as well as stakeholders in medical research. It seems ironic if we were to say medical research, which is in effort for the benefit of patients, to source its information from the patients it intends to save. Granted concerns with how these new WEB 2.0 tools will be used are valid, but much like a hammer, tools can be used for creation or destruction, it depends on who is using them and how.

A more difficult question would be who decides, who can use these tools, and who gives them the authority to make such a decision. Which is *"why many patients find all this talk of consequences and concerns immaterial and patronizing."* (Arnst, 2008, para 26). As a 40-year-old ALS patient, Steven Sailing, says *"Current HIPAA regulations, while well intentioned, keep researchers from connecting the dots to understand what causes ALS"* (Arnst, 2008, para 27).

TABLE 21 - PatientsLikeMe Member Testimonials © Patientslikeme.com, 2014

ANSWERS FOR OTHERS LIVING WITH MY DISEASE

I AM WILLING TO SHARE MY MEDICAL DATA...BECAUSE I GIVE ANSWERS TO THOSE WHO HAVE THE DISEASE WHO HAVE TO LIVE WITH IT.

APRIL 11, 2014

EXTREMELY EXCITED TO FIND PATIENTSLIKEME

I WAS EXTREMELY EXCITED TO FIND PATIENTSLIKEME AND TO FIND OUT THERE WERE OVER 30,000 PEOPLE WITH MS CONTRIBUTING INFORMATION TO THE SITE. I BELIEVE THAT THIS TYPE OF COLLABORATION WILL GREATLY ACCELERATE THE DISCOVERY PROCESS ON MANY FRONTS - FINDING THE CAUSE OF DISEASE, TREATING THE DISEASE, AND REVERSING DAMAGE.

MARCH 28, 2014

SHARING MY INFO IS THE BEST WAY TO PAY IT FORWARD

I REALLY LOVE HAVING ONE PLACE WHERE I CAN GET A COMPLETE PICTURE OF WHAT'S GOING ON — NOT JUST TEST SCORES OR SYMPTOMS, BUT ALSO HOW I'M FEELING IN RELATION TO EVERYTHING. THE VARIOUS QUESTIONS HELP ME TUNE INTO MY MENTAL, EMOTIONAL AND PHYSICAL STATES. AND THE MORE I UNDERSTAND ABOUT WHAT'S HAPPENING WITH ME, THE BETTER INFORMED I CAN KEEP MY DOCTORS, AND THAT HELPS EVERYTHING. AS FOR DONATING DATA, I AM HAPPY TO DO IT. THE TREATMENTS AND TECHNIQUES THAT I AM BENEFITING FROM TODAY WERE DEVELOPED WITH INFORMATION FROM PATIENTS WHO CAME BEFORE. SHARING MY INFO IS THE BEST WAY I CAN THINK OF TO PAY IT FORWARD.

MARCH 14, 2014

I'M WILLING TO BE TRANSPARENT, OTHERS WILL BE INSPIRED

SHARING MY HEALTH INFORMATION WITH THE COMMUNITY IS PART OF BEING AN ADVOCATE. IF I AM WILLING TO BE TRANSPARENT, HOPEFULLY OTHERS WILL BE INSPIRED TO DO THE SAME. TOGETHER, WE ARE SOLDIERS IN THIS BATTLE AGAINST MS. SHARING HELPS ME TRACK IMPORTANT HEALTH INFORMATION AND IMPROVE RESEARCH ABOUT THIS DISEASE. IT'S VERY EASY FOR ME TO DO, AND I CAN EVEN DO IT FROM MY PHONE. IN TURN, IT BENEFITS US WITH NEW TREATMENTS AND WAYS TO DEAL WITH MS. I GET EXCITED JUST THINKING ABOUT IT.

FEBRUARY 7, 2014

The privacy issue will become more imperative as Health 2.0 grows and members of websites like PatientsLikeMe reach the millions, raising the probability of one patient having a bad experience to cause a change in culture (Arnst, 2008). However many experts believe that even such an event will unlikely result in people refraining from networking and sharing data, as Trevor Novartis, global head of development for Novartis Pharma AG, says *"Patients will keep pressuring all of us in the direction of more openness"* (Arnst, 2008).

The more pressing issues that arise from patient empowerment are not in privacy but in misinformation (Goetz, 2008). Who guarantee that the information that patients are sharing is accurate and won't lead to patients testing unproven or dangerous medication, treatments or dosages? (Goetz, 2008) What is the role of doctors, and how will it change the patient-doctor dynamic when PatientsLikeMe information contradicts a physician's diagnosis or treatment? (GOETZ, 2008) What happens when WEB 2.0 generated data contradicts clinical research? (Goetz, 2008) *"What's to keep patients from misinterpreting the streams of data and finding false hope"* (Goetz, 2008, para. 9)

In the face of growing health network users and the emergence of the internet as a source of medical information, where 80% of internet users [113 million adults in the U.S] use the internet for health information, the medical community worries this trend will create a boom of 'hyper-informed' patients, a phenomenon we do not know how it will end up impacting healthcare (Goetz, 2008).

"PatientsLikeMe is committed to putting patients first. We do this by providing a better, more effective way for you to share your real-world health experiences in order to help yourself, other patients like you and organizations that focus on your conditions."

(Patientslikeme.com, 2014)

5.2 REAL WORLD RESEARCH OR MISINFORMATION

As covered before, PatientsLikeMe is a valuable and sophisticated processing tool to mine through data submitted by patients (Singer, 2010). The data can be used for developing and improving pharmaceutical, medical technology and other products as it is derived directly from patient statistics and opinions (Singer, 2010). When a possible side effect or product irregularity could take years to emerge upon entering markets, having *“real-time information from real-world patients may also provide an early warning signal for drug safety problems”* (Singer, 2010, para. 1). Companies, governments, universities, research labs, hospitals, physicians and other medical experts can use the information gathered by websites like PatientsLikeMe in order to gain instant feedback from actual patients who are trying new medication, alternative treatments or expressing opinions that might affect even funding into research of a specific disease which is not gaining enough awareness (Singer, 2010).

Today there are limitations to accessing data which PatientsLikeMe hold responsible for the slow progress in medical research. Beyond the privacy and copyright limitations which obstruct open access to information for patients, and more importantly physicians, the sheer number of clinical trials which result in dozens of different medications and volumes of scientific literature makes it impractical and nearly impossible for doctors to be kept up to date. Each clinical trial will have its own data which might contradict other research and *“a single study is rarely enough to be conclusive [...whilst...] negative studies are considerably harder to get published than positive studies, resulting in bias in the scientific literature”* (Wicks, 2014, point. 22). PatientsLikeMe believes the appropriate and fast method to conduct medical research is through meta-analysis of multiple studies. Meta-analysis involves combining data from more than one independent clinical trial at random in order to overcome bias and achieve research transparency. (Crombie, 2009).

PatientsLikeMe believes there is much to benefit from a transition of independent clinical trial results and *“inaccessible records of unstructured text, tables, and graphs of the average to an open repository of machine-readable data to permit ongoing research, re-analysis, scrutiny, and meta-analysis.”* (Wicks, 2014). In reference to Amazon, Paul Wicks state *“if we can do it with a washing machine, why not medicine?”* (Wicks, 2014, point. 25).

With Meta-Analysis patients can evaluate medication either through personal testimonial published online or through results in their health published through the data collected on their profile, thus allowing pharmaceutical companies to detect problems that might not show up in trials. At the same time impact a medication might have would be visible to the website members as they are kept up to date with their community news feed. When patient normally have to wait years for clinical trial results for their disease, PatientsLikeMe provides a way for them to actively monitor and participate in research based on their own figures. The figure below is an example of a Meta-Analysis study. Each independent trial study is listed. The findings are represented by blobs, or squares, whose size represents the sample size of the study. The horizontal line represents the level of uncertainty in the treatment effect. An average is established by the study results and uncertainty to reveal the combined result as a diamond.

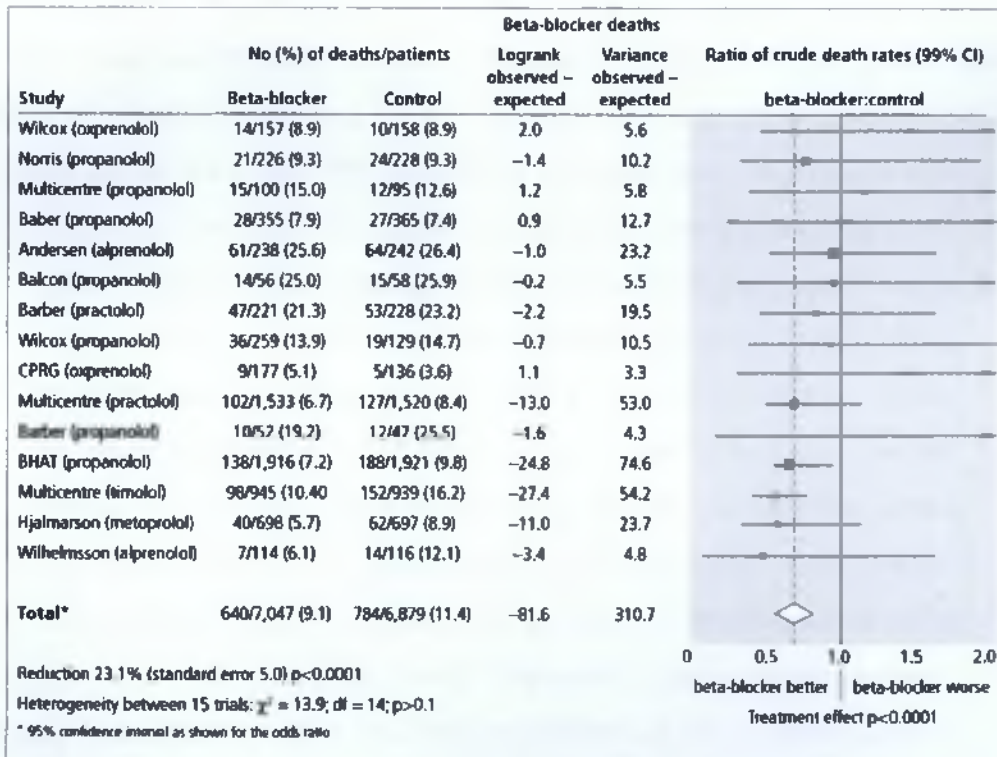


Fig 8. To the left is an example of a Meta-Analysis study. Each independent trial study is listed. The findings are represented by blobs, or squares, whose size represents the sample size of the study. The horizontal line represents the level of uncertainty in the treatment effect. An average is established by the study results and uncertainty to reveal the combined result as a diamond.

PatientsLikeMe has *“published over 30 peer-reviewed scientific studies in clinical trial design, off-label drug prescribing, the development of new patient reported outcome measures, and barriers to medication adherence”* (Wicks, 2014, point 19). A fact which is alarming to the neurologist Erik Ensrud, as he states in an article of the New York Times, *“Even if a treatment seems promising, it could result in a very serious reduction in lifespan [...] We’re talking survival”* (Goetz, 2008, para. 34). Ensrud worries that the increase of patient to patient communication and unsupervised access to medical information online can lead more desperate patients to self-medicate, based on an animal study or early-stage clinical trials in hope the researches are finding a cure (Goetz, 2008).

Ensrud’s worries are not unwarranted. In 2007 researchers in Italy announced without having published the study yet that lithium could slow the progression of A.L.S (Goetz, 2008). The vulnerability of patients who suffer from A.L.S led a small group to being their own patient run trial by obtaining lithium prescriptions from their doctors in hope the research would provide a cure (Goetz, 2008). The patient run trial was sparked by a 42 year old Brazilian man named Humberto Macedo, who was diagnosed in March of 2007 with A.L.S. (Arnst, 2008).

“Macedo was confined to a wheelchair, barely able to speak, soon after he was diagnosed. He could still use a computer, though, and he quickly joined the ALS group on PatientsLikeMe. Researching his condition on the Internet, Macedo discovered a report on a small Italian study in which lithium appeared to slow progression of ALS. No company would be willing to finance a confirming trial of a drug that went off patent decades ago, against a disease that strikes only 4 to 8 people per 100,000. So Macedo stepped up, proposing to fellow PatientsLikeMe members that they test it themselves.” (Arnst, 2008, para. 8)

Macedo posted on his PatientsLikeMe profile his daily vital signs, recording any and all symptoms (Arnst, 2008). Other PatientsLikeMe members suffering with A.L.S began taking lithium and posting the results, leading the participants of this patient run trial to soon reach 250, which was 5 times as many as in the Italian research group who made the initial statement (Arnst, 2008). Doctors were unwilling to comment on results nor did any journals accept to publish them, but as Macedo

stated *"...we can't count on medical experts to get interested in ALS, and we don't have any time to lose [...] at least we have tried something to help ourselves."* (Arnst, 2008)

The main reason journals did not accept any results posted by the patients was due to the fact that they were able to see other patients results on the website which could affect how patients documented their vitals leading to false results (Marcus, 2011). In clinical trials patients are randomly assigned to treatments or the control group (Marcus, 2011). In order to reduce any bias due to the lack of randomization, and to address the concern of the medical community, Patients like me developed an algorithm to cross examine the results of A.L.S patient who took Lithium with those who did not (Marcus, 2011). They monitored the lithium blood levels in 447 patients, 149 of which were taking Lithium. Additional data were collected from each patient whether they were swallowing, walking or breathing, a process which lasted for 12 months (Marcus, 2011). The study revealed that lithium made no difference in the disease progression between patients taking lithium and the control group (Marcus, 2011).

Later a clinical trial was carried out to test the effect of lithium on 596 patients suffering from A.L.S officially showing the drug did not affect the progression of the condition, contradicting the Italian study and supporting the findings of the patient run trial of PatientsLikeMe (Marcus, 2011). The study was published in the journal of Nature Biotechnology and proved a very important example of how patient run research through data collecting social networks such as PatientsLikeMe could accelerate clinical research and the evaluation of pharmaceuticals which are already in circulation (Wicks, et al. 2011).

However one cannot fail to address that the Lithium patient trial should be considered lucky due to the fact there were no side effects which in a clinical environment could be dealt immediately. If a patient was to experience a violent side effect at home they may not be able to respond in time, leading to a fatal conclusion. Not to mention the risk of side effects affecting long term outcomes which could either be linked to the trial, or go entirely unnoticed to the general public.

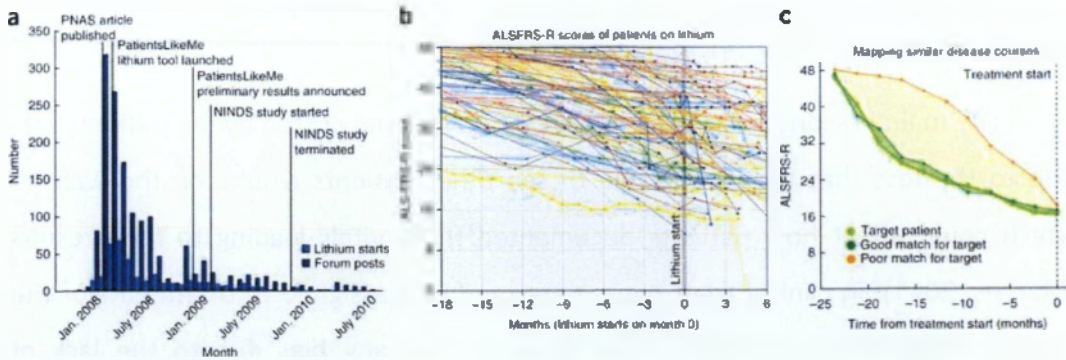
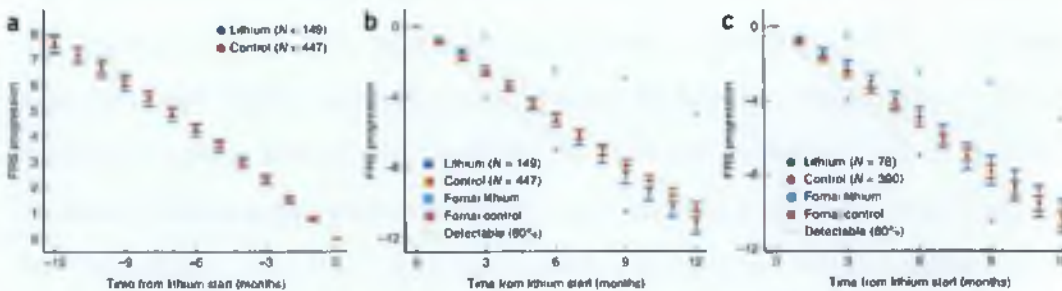


Fig 9.
 (a) The number of patients choosing to experiment with lithium carbonate peaked in the months after publication of a small clinical trial in Italy.
 (b) Aggregate view of FRS scores for all 348 patients analyzed in this study.
 (c) Illustration of disease progression curves of control individuals that are good and poor matches for a particular patient.

(a) Summary of pretreatment disease progression curves for 149 intent-to-treat patients matched by the PatientsLikeMe matching algorithm.
 (b) Intent-to-treat analysis of 149 patients treated with lithium carbonate compared with controls fails to find any significant differences in progression
 (c) Full-course analysis of 78 patients treated with lithium carbonate compared with controls fails to find any significant differences in progression.
Fig 10.



The other risk of misinformation is the intentional statement of possible cure by a pharmaceutical company in order to conduct a clinical trial for free and most importantly without responsibility as the patients will be testing the drug at their own consent. To be fair this is a phenomenon linked entirely with the access of medial information online, however websites such as PatientsLikeMe do have the capability to inform and guide patients away from potentially dangerous untested alternative medication. As the Journal of Biotechnology stated in respect to how patients quickly volunteered to test the Lithium drug,

"For patients with limited life expectancy, the ability to participate in a very rough, low-level clinical study on a new treatment is far more appealing and timely than waiting for clinical data"

(Arnst, 2008, para. 11)

Although the findings of the Lithium experiment are promising, there are still challenges in assuring bias reporting, misinformation and responsible health and safety (Brownstein, 2009). PatientsLikeMe insists it did not encourage A.L.S members to test the lithium cure, however they cannot hide the fact they are excited by the results as experiment *"perfectly illustrates how PatientsLikeMe might complement large-scale and long-term clinical research by conducting observational research"* (Goetz, 2008, para. 35).

"The system is broken for terminally ill patients [...] It makes us wait five to seven years for results, when we don't even have that time. Even if it's half-true, it's still groundbreaking. I don't want to wait for something else. I don't have time to wait." Mr. Riederer A.L.S patient

(Goetz, 2008, para. 35)

United States spends \$12 billion a year on antidepressants with little if any understanding of if and how they work. Pharmaceutical companies can take advantage of the lack of information by falsely marketing the drug on a placebo effect, whilst patients have no way to properly evaluate the effects (Goetz, 2008). Accordingly, in 2006, the National Institute of Mental Health published the results of a study which rejected the traditional method of clinical trials and aimed to carry out a study based on real-world data revealing whether any of the actual pharmaceuticals worked via a trial and error method, taking one product at a time until they found one that works. The study was inconclusive with a 50% chance of achieving a positive outcome after 6 months which also came with a list of possible side effects (Goetz, 2008).

Ben Heywood from PatientsLikeMe, says *"Those odds just aren't good enough [...] so you try Wellbutrin, and after six weeks it doesn't work. Then Prozac. Doesn't work. Now what? Where do you go next?"* (Goetz, 2008, para. 26). He also mentioned that by being part of an online community like PatientsLikeMe, patients suffering from depression can share their stories and treatments so that individuals looking to compare pharmaceuticals do not have to try them all themselves, but

rather find people with the same medical history, who have tried them and review their results (Goetz, 2008). Lee Hartwell, a Nobel prize winning scientist formerly president of the Fred Hutchinson cancer Research center and now at the Arizona State University, where traditional clinical trials are part of their research process, states that the approach has tremendous potential (Marcus, 2011). While Dr. Hartwell does not expect that social-network trials will “*replace conventional randomized, double-blinded, placebo-controlled trials, the gold-standard for generating medical evidence*” he does acknowledge that traditional methods are become complicated and slow and newer methods are needed (Marcus, 2011).

PatientsLikeMe’s Paul Wicks states that the traditional method and the one of social networks is not a matter of one or the other, but rather that social network trials can function to providing testing for ‘off-label’ and ‘off-patent’ medication which pharmaceutical companies might not be showing interest for financial reasons, but might hold value for medical purposes (Marcus, 2011). There is special interest in the financial motives of websites such as pharmaceutical companies in contrast with patient social networks such as PatientsLikeMe. Both are for profit, however the pharmaceutical companies depend on sales whether generated by more or less patient information, like in the case with anti-depressants, whilst PatientsLikeMe’s depend on the amount of information it gathers from patients willing to participate. It seems that PatientsLikeMe’s and a patient’s incentives are in parallel given that if patients see no outcome from patient trials, then PatientsLikeMe runs out of business.

So far the pharmaceutical industry does not seem to embrace the patient driven trials possible because it simply does not want to know what happens when their products reach the market (Goetz, 2008). PatientsLikeMe method of trial would advocate a more responsible and transparent method of drug manufacturing, which in comparison to today’s industry might be less profitable (Goetz, 2008). Also, it should be mentioned that sometimes, patient side effects could lead to medical breakthroughs. This was the case when scientists learned that their hypertension treatment was causing erections in men, leading the way to Viagra (Goetz, 2008). As mentioned before, the effort to recruit and carry out clinical trials is not only time consuming for patients but for pharmaceutical companies too, speeding up the

process will both cut costs for the industry and lead to faster investment returns (Marcus, 2011). The reverse outcome is also a risk, where the initial study might not show positive impact, but the patient trial reveals that it does.

"The thing you don't want to do in a fatal illness is to throw out potentially good drugs that might have small but meaningful effects."

Merit Cudkowicz ALS researcher Harvard Medical School

(Marcus, 2011, para. 18)

Dr. Cudkowicz was part of the official clinical trial on the impact of lithium on A.L.S patients and has supported the insights websites such as PatientsLikeMe can offer, however she agrees with Dr. Hartwell that patient run trials will never substitute the conventional methods (Marcus, 2011). In the end of day medical social networks such as PatientsLikeMe offer support and strength for patients who deal with chronic deceases. As witnessed with the emergence of WEB 2.0 medical information is becoming ever more accessible by the general public through social media such as bogs, wikis and forums. This information carries the risk of misleading, exploiting or being misinterpreted by patients. However if the information is organized structured and used by medical experts and industry, the social networks can become a revelation with communities and medical stakeholders *"forged not only around shared circumstance but also around a shared purpose."* (Goetz, 2008)

"If we could gather in structured communities and create databanks to inform our approach to life decisions, not just health decisions but also gardening or parenting or car-buying decisions, we could do everything in a more informed manner. Were we all to a vow a philosophy of openness and churn our experiences into hard numbers, we could presumably improve our odds in all sorts of decisions. Why not a PregnantLikeMe or a ParentsLikeMe or even, really, an all-encompassing PeopleLikeMe?"

(Goetz, 2008)

The author of the 2008 New York Times article *Practicing Patients*, Thomas Goetz, deputy editor of Wired magazine, met Jamie and Ben Heywood and shared his idea a of PregnantLikeMe, ParentsLikeMe and PoepleLikeMe and they both looked back at him and said, "We know [...]. We already own all those domain names." (Goetz, 2008, para 54.)

CHAPTER 6: THE FUTURE OF HEALTH CARE ONLINE

6.1 - THE FUTURE OF PATIENTS LIKE ME

With its framework in place and now firmly established with over 300,000 members, the next step for PatientsLikeMe is to grow (Patientslikeme.com, 2014). Its priority at this moment is to increase the number of members and increase patient participation (Zeliadt, 2014). With more patient participation it can improve its real-world results which subsequently will prove to both its members and clients that its services are worth investing (Zeliadt, 2014). This justifies why PatientsLikeMe is currently developing a range of new and improved tools *“for pharmaceutical companies to help improve their products and services [...whilst empowering...] patients to improve their outcomes, and ultimately changing the pace and quality of evidence-based medicine.”* (Brownstein, 2009, para. 13)

To achieve this, Patientslikeme is currently establishing a series of new longer term partnerships with the pharmaceutical industry. In May of 2014, Genentech, a subsidiary of pharmaceutical company Roche, committed to a 5 year partnership with PatientsLikeMe (Zeliadt, 2014). This will grant to the company full access rights over the platform collected data aiming to learn the effectiveness of their

pharmaceuticals (Zeliadt, 2014). This partnership, and many other long term partnerships to come, are the results of PatientsLikeMe’s Global Network Access (News.patientslikeme.com, 2014). While previously PatientsLikeMe would provide specific data collections to its partners, the company has setup a tool which now allows full access to its network. The broad network access service will be provided for a selected number of companies. The services will be presented to its partners as a partnership with patients rather than treating patients a subjects, which has lead PatientsLikeMe to not only grant such access to its partners, but also give an even bigger voice and representation to its clients (News. patientslikeme.com, 2014)

“Our collaboration with PatientsLikeMe will allow us to learn more from patients with serious diseases, and better integrate their insights into our decision-making.” Bruce Cooper M.D., senior vice president, Genentech

(News.patientslikeme.com, 2014)

In March 2014, PatientsLikeMe conducted a survey on 1,621 members asking them about their opinion either on experiences they have had with clinical trials or what criteria would convince them to partake (News.patientslikeme.com, 2014). 1 out of 5 responded they had taken part in a clinical trial before, 1 in 5 of that group who had participated in a trial expressed they were unsatisfied by the experience (News.patientslikeme.com, 2014). However 9 out 10 responded they would be willing to help design better trials with 8 of 10 being willing to participate in one in the next 12 months. According to these results PatientsLikeMe announced three new services in June of 2014 (News. patientslikeme.com, 2014).

TABLE 22 – PatientsLikeMe new services © News.patientslikeme.com, 2014

<p>Trial Access</p> <p>Which allows pharmaceutical companies to develop and deploy custom research programs that gather meaningful data and feedback on the design of their clinical trials. Trial Access also includes review of an expanding repository of patient opinions and attitudes about participating in clinical trials.</p>
<p>Community Access</p> <p>Which pairs researchers with PatientsLikeMe scientists and patient engagement experts to build open, online registries for research to gain insights from patient-reported data that can be shared across the organization.</p>
<p>Access Services</p> <p>Which allows companies to quickly collect and analyze real world data to generate statistically robust and scientifically credible patient outcome research, and determine the impact of new wearable and consumer-oriented health devices and sensors on clinical development and commercialization.</p>

The company also launched in September of 2014 its first patient-led Team of advisors. The team will act as representatives of the PatientsLikeMe community as a whole, including a diverse demographic sample, consisting from veterans, nurses, social workers and academics of varying ages and gender (News.patientslikeme.com, 2014). Each representative will also come from different disease communities thus representing patient communities fairly.

The team will meet in person, spending the next 12 months providing feedback and publishing guides which will outline “standards for how researchers can meaningfully engage patients throughout the research process” (News.patientslikeme.com, 2014). This could be the first step towards a parliamentary like system where delegates represent individual disease communities in a ‘democratic’ healthcare system. In such a system, patient data would be abundant and could be accessed as a whole on a global level prioritizing research, allocating funding, managing efficiency and containing disease outbreaks. In return, health care costs can be managed efficiently making affordable, accessible and educational for as many people possible.

“We envision a world where information exchange between patients, doctors, pharmaceutical companies, researchers and the healthcare industry can be free and open; where, in doing so, people do not have to fear discrimination, stigmatization or regulation; and where the free flow of information helps everyone. We envision a future where every patient benefits from the collective experience of all, and where the risk and reward of each possible choice is transparent and known.”

(PatientsLikeMe help center, 2014)

Web 2.0 and the social platforms that have evolved through it such as PatientsLikeMe, Wikipedia, Facebook and Twitter have exposed a “clash between common-based technology platforms and the imperatives of the larger market economy in which they exist” (Gorbis, 2013, p182). With WEB 2.0 our technology is moving ever more towards a highly participatory and social construct, ‘a socialstruct’ (Gorbis, 2013). Companies such as the above have identified and taken advantage of an aspect in human nature and have incorporated it into their technology and business model. That aspect of human nature is the motivation to “contribute in

order to be noticed, to share opinion, to be a part of something greater than ourselves" (Gorbis, 2013, p182). Business models in the past have entirely been based on market input, where money coordinated the flow of goods, services and specifically information. With businesses expanding into WEB 2.0, information has become a commodity which people are freely contributing with little monetary reward but rather larger social rewards. In socialstructs we see information being the commodity which drives flows rather than currency. Production will not focus solely on the maximization of profit, but will be rather aimed to contribute and solve large scale problems, such as disease, in order to create happiness and prosperity in society (Gorbis, 2013). These flows will be based on micro-contribution by individuals, part of a large network, creating a bottom-up approach to marketing and product design where market research is not hypothesized but gathered from huge amounts of data. This will lead to consumers, or patients in the case of PatientsLikeMe, having more control on what is created and subsequently what they buy. The number of such socialstruct businesses is believed to grow considerably in the future as the technology diffuses into the society increase the flow of information which drives it. We could even witness socialstructs overshadow the market-based method of production as its flow of information allows for better and faster innovation whilst satisfying people's motivation to contribute (Gorbis, 2013).

"What is different in the new symbiosis is that the socialstruct will be producing things that were previously produced in the money economy draining value out of existing institutions and becoming dominant models of value creation." (Gorbis, 2013, p189)

Whilst many suggest there will be much tension in this symbiosis between socialstructs and traditional business, PatientsLikeMe might prove otherwise. In contrast to other socialstructs, or even other patient-centric data collection platforms, PatientsLikeMe *"is focusing on measuring the trajectory of the human experience in a robust and computable way"* (Zeliadt, 2014). This allows them to create information and data of value for both research and marketing. Thus PatientsLikeMe falls in-between the two conflicting models and perhaps even connects them. Humanizing a corporate private sector and optimizing the more

social public sector. PatientsLikeMe phrase it best when they say they are, ‘for-profit company, with a not-just-for-profit attitude’.

Therefore the future of PatientsLikeMe will rely on the development of data collecting technology to encourage patient participation. As the company grows its product will increase in value and so will the rewards for its members, and healthcare in general. Therefore, if the technology evolves, allowing for better healthcare, as a result of more data, this will lead to further participation. In other words, the future of PatientsLikeMe and healthcare in social networks depends solely on how the technology will develop. How will the technology develop in order to increase the speed and volume of information shared on the WEB? To what extent will we be connected to the internet, given we have entered an age of smartphones and mobile data capturing devices? These are questions which, in a society where healthcare and social networks become ever more connected, will impact not only the quality of healthcare but the way it works.

“I think you'll be looking at a global registry with hundreds of millions of individuals that's been translated into every language and normalized to local traditions and that's fully integrated into the medical system so it's part of care and incorporates information from the electronic medical record, imaging, diagnostics and emerging technologies for interrogating biology. Everyone says we have to spend less on health care, and I'm not sure I agree with that—there's nothing more important in life than health. What we need to do is get more value for health care, and value means you have competitive outcomes. And that's what, in our longest dreams, I think PatientsLikeMe begins to bring to bear.”

Jamie Heywood - Co-Founder, Chairman PatientsLikeMe

(Zeliadt, 2014, para. 8)

6.2 - HEALTHCARE IN WEB 3.0

Today there are over 1.8 billion smartphones in the world. Ever since mobile technology has connected to the internet “*people unconsciously generating more data about themselves than ever before*” (Olson, 2014, para. 36). This creates a huge opportunity for socialstrcuts to tap into as a source of data. Wearable devices, or smartphone apps are being developed and marketed to people who need to monitor their health and fitness, access medical information, receive reminders or encouragements whenever and wherever they may be. There are over 5,800 different fitness and health smartphone applications that provide tracking, alerts, and reminders or even log vital signs (Turisco, 2011). With smartphone access to the web, patients now have a tool which they can carry with them almost anywhere which grants them at any time, as long as they have Wi-Fi signal or 3G, to their online medical records, their health care social networks, healthcare databases and all the feature provide by WEB 2.0. Currently there are five categories of functions provided by health care apps on smartphones (Turisco, 2011).

TABLE 23 © Turisco, 2014, CSC

General content
Information for a general audience that targets the wellness objective. This includes tips for quitting smoking, dieting and administering first aid.
Customized content
Information specific to the service and individual. This includes personalized meal plans medication schedules and exercise regimens.
Push messages
Reminders, motivational messages and alerts when there is a clinical problem
Data capture
Activity data such as fitness activities vital signs and the patient’s information. Data are stored and can be trended overtime.
Interactive services
Advice and recommendations such as food selections, location of closet emergency room, and direct communication with care professionals. Data are sent from the device to a central repository and other clinical systems.

For platforms like PatientsLikeMe, the opportunities in the information gathered from smartphone healthcare applications are endless. From boosting health and fitness by assessing metabolic rate based on the distance a person walks, bikes or runs every day, down to monitoring workout sessions and diet measuring calorie intakes and weight. This information cross referenced against medical conditions could not only provide an endless global network of constant clinical trials providing information on how disease, treatment, lifestyle affect physical output (Turisco, 2011). Based on that information, medical content can then be generated for patients to review and make changes in their lifestyle to achieve health and fitness goals, or even send emergency notifications if a certain way of life is worsening a medical condition or even creating one (Turisco, 2011). Heart rates could be checked remotely without having to physically visit a physician; in fact multiple physicians could have access to your data thus having more than one opinions at any time (TURISCO, 2011). Misinformation could be red flagged by conquering physicians and patients. Pharmaceutical companies would be monitored by patients as they would be susceptible to negative press a drug cause side effects, as it would show up on the platform from patient testimonies. The technology for the above possibilities already exists independently as separate apps and devices (Turisco, 2011)

“A holistic closed-loop team solution for wellness and health management. This involves a cadre of health, wellness and family members connected using technologies that share data, provide knowledge and alert team members when an event (that is relevant and important to them) has occurred.” (PatientsLikeMe help center, 2014)

In 2011 PatientsLikeMe released a mobile app for its platform called ‘InstantMe on the go’, a follow up from previous service which involved a quick response survey via email asking ‘how are you feeling?’ (Blog.patientslikeme.com, 2014). This small stream of data was then uploaded to the rest of a member’s profile information giving a frequent updating connection between patients and their profiles. Initially the mobile app was alpha tested on its most active members. Upon receiving feedback two new features were introduced, a chart diagram showing how you have felt over time, and clinical trial search feature. The app is still in its infancy

but with the infrastructure already in place, the technology exists and the opportunities are evident (Blog.patientslikeme.com, 2014).

In the near future, members of PatientsLikeMe will be live streaming information into their profiles monitoring every detail of their health whilst providing valuable information and support for other patients and the healthcare system. This will significantly change the entire dynamic of healthcare, not only in terms of data for research and patients support, but will create new opportunities in resource management for patients who need constant monitoring.

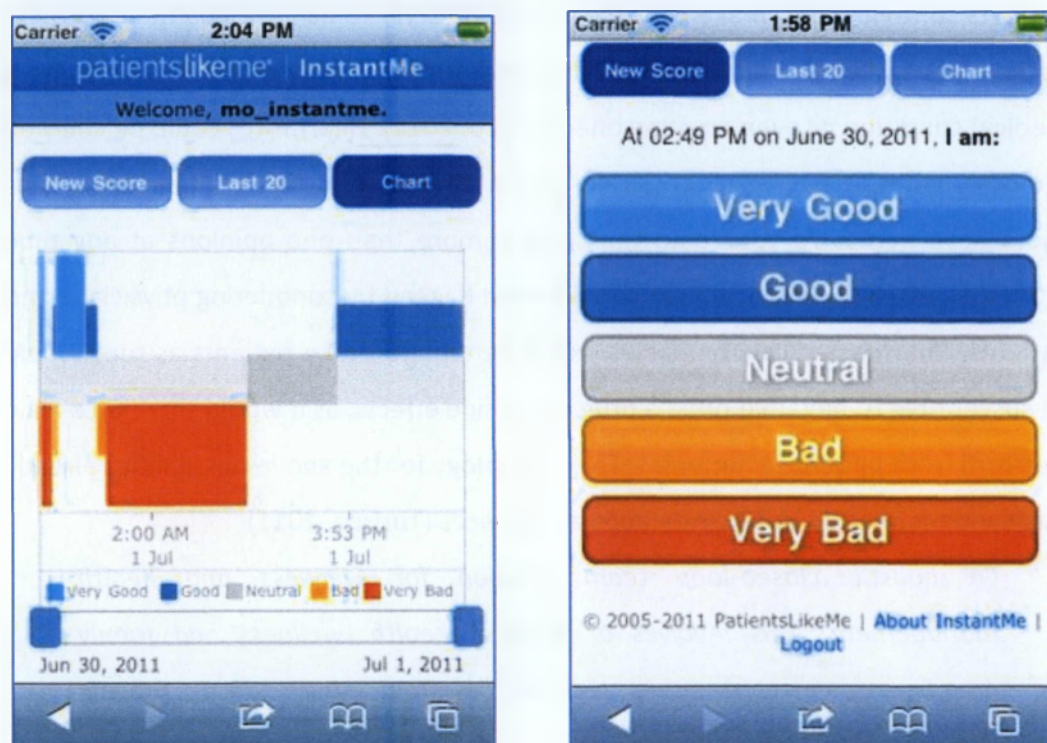


Fig. 11 - InstantMe smartphone app. [left] Charted responses [right] Choice of answer.

For patients who require constant care and monitoring, the combination of a platform such as PatientsLikeMe and mobile devices provides a cost effective solution. With more serious medical conditions, medical costs can reach a point where a patient does not have the resources or insurance receive the require care. Some conditions require *“nurse transition coaches, who call patients and make house calls to help them understand medication changes, arrange follow-up appointments, and ensure that patients are keeping up with therapy or dietary requirements”* (Turisco, 2011, p11). The patient–interactive approach will

interconnect patients with physicians and industry to achieve efficient and quality health care.

“The technology reminds the patient to enter daily vital sign and health information, sends the data, and analyzes the findings, and alerts transition coaches and care providers only when patients need their help. For post-acute care the smartphone is not typically the patient device of choice; it is an internet-connected home pc with medical devices attached to help the patient collect vital signs.” (Turisco, 2011, p11).

Over the next 5 years, the remote patient monitoring device market is estimated to deliver 950 million in revenue. These devices can both monitor vital signs but also include capabilities to send information directly to physicians allowing them to intervene if necessary. One of these devices is the smart bandage which is stuck to the patient’s skin in order to monitor and transmit real-time information. The information can then be uploaded through a mobile device or computer with an internet connection to the patients’ health records, whether at a hospital, physician’s office or even health care social network (Turisco, 2011). Streams of such data coming from multiple patients will provide new insight into treatment method, lifestyles and even psychological behavior over any desired period of time. Whether it be across a year, a decade or even a week, researchers and physicians will be able to monitor the impact of healthcare decisions immediately. Thus allowing them to fine tune the healthcare system based on real data, and not profit margins and placebo drugs or patient misinformation (Turisco, 2011). The devices can measure cardiac data, blood pressure, temperature, respiratory rate or even monitor medication intake (Turisco, 2011).

Many physicians have problems with patient’s non-compliance, or patients who forget if they have taken their pill, or need medication to target a specific part of the body or release at a specific time. Philips has been developing a smart pill which can be programed to deliver to medication to targeted areas of the body by measuring PH levels. The device can even release medication at one burst or over time in small doses targeting multiple locations.

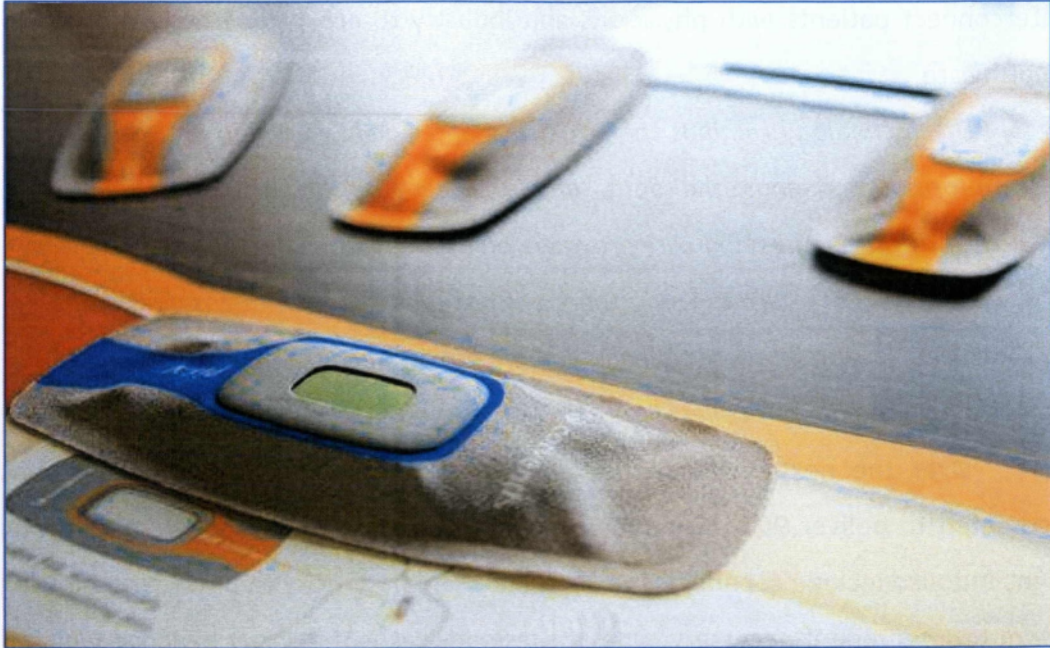


Fig 12. Smart band aid 'PIIX' developed by Corventis. Smart bandages, including this one, can transmit cardiac data in real time from a patient's body to a doctor.

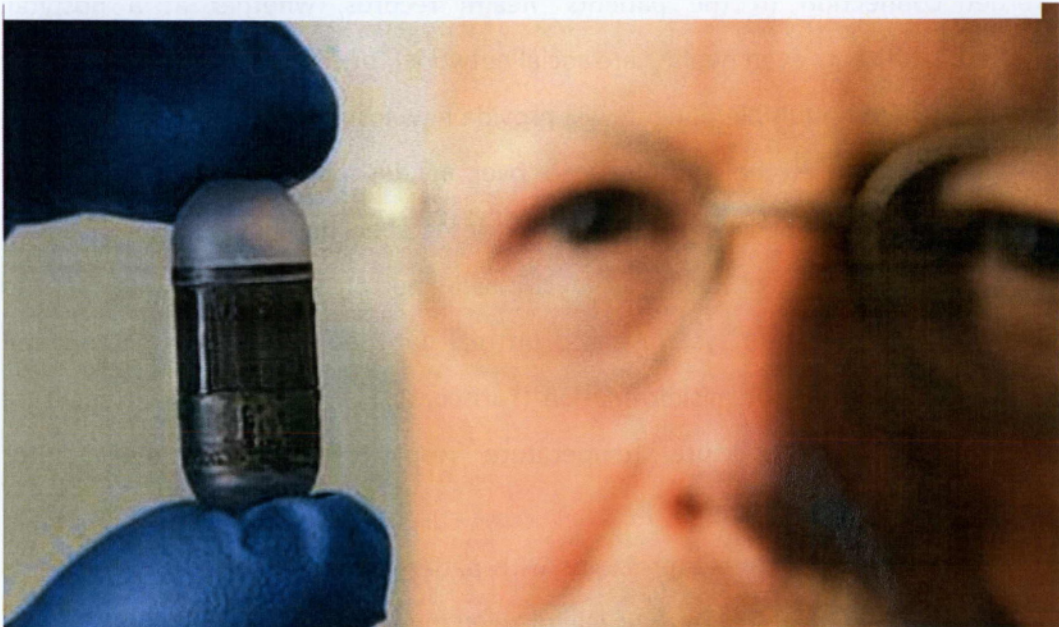


Fig 13. IntelliCap technology features real-time wireless data recording, plus wireless remote control of dose profiling, giving researchers the ability to monitor an IntelliCap's progress through the GI tract and direct the delivery profile 'on the fly'.

The smart pill is being developed to even recognize and target damaged cell such DNA defects in cancer cells. In combination with monitoring devices and WEB platforms which can analyze the data, patients, doctors and pharmaceutical companies can monitor the reaction and outcome of targeted treatment and pharmaceutical improving healthcare at low costs, without consuming huge resources. Patients will become partners monitoring their health, whilst physicians are mostly supervise their patients and meeting with them less often allowing them to care for more time for those in need (Turisco, 2011).

Also, Google Glass developed a set of tools for remote consultations, record keeping, patient monitoring and medical collaboration. In a short film presenting its application, a man suffering from a stroke is attended to by the paramedic whilst the expecting physician monitors remotely. The physician uses *“the device to call others, pull up medical records, record videos and photos of the patient, take live speech-to-text dictation notes, and even teleconference with specialists”* (Dvorsky, 2014).



Fig. 14 - Short film depicting the use of Google glass by medical staff in an E.R.

“I want an electric sensor on your head, in your toilet, on your pancreas, on your steering wheel and in your Google Glasses [...] our goal is to build a learning health care system.” Paul Wicks- Vice President of Innovation

(Upbin, 2013, para. 8)

This combination of data collecting technologies, communication devices and social platforms are leading healthcare to a new era of WEB 3.0, otherwise known as the semantic WEB (Hyett, 2010). WEB 3.0 and its definition are a topic of debate. A popular belief is that the era of Web 3.0 will be when computers, rather than humans, will be generating new information. Computers will have the ability to make meaningful connections, identify patterns, and do all the time consuming work in order to produce the information people want. Based on this idea it is suggested that WEB 3.0 is not far from today. It might be closer than we think, as all our wireless and smart devices are gradually interconnecting through platforms which can process vast amounts of data into meaningful information (Hyett, 2010).

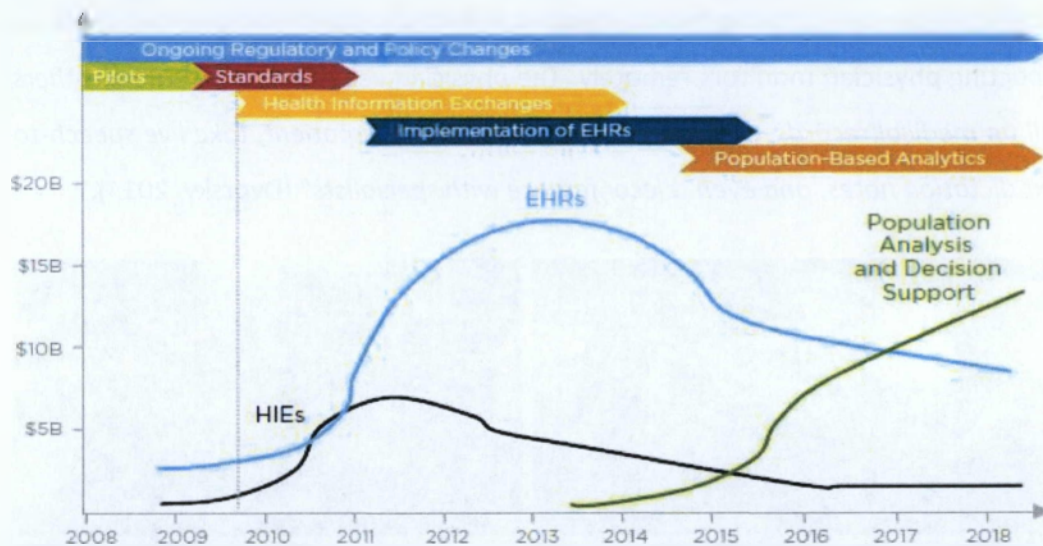


Fig. 15 - Three waves of health information technology investment: health information exchanges, electronic health records and tools for health analytics.

Skeptics worry about possible negative impacts that may come with population-based analytics, with regards to whom might have access. Besides privacy or misinformation, another issue that will arise with technology merging into a semantic WEB is other parties finding an interest in using it for capital gain. Health insurance companies stand to profit from accessing such information as they could check client health profiles to raise or lower their insurance fees based on their diet or life style. At a time where insurance fees fluctuate yearly, we could witness insurance fees being set on daily basis depending on the amount of monitoring and data. Tracking gadget have already been used by car insurance companies on

dashboards of cars to monitor a client's driving to determine whether they are eligible for insurance discounts (Olson, 2014).

"I can see health care going that way [...] If you can take this wearable and I can see a constant level of activity and constant parameters on fitness activities, I'll take points off your premium... I can set rates on a daily basis as opposed to just once a year."

BARNES PricewaterhouseCoopers

(Olson, 2014, para. 14)

While there may be many benefits with greater monitoring, society must keep a watchful eye on its development to prevent unintended consequences. As mobile devices will transmit every more health data, there will be constant risk that this data could leak, which will both lower its value and risk insurance companies gaining access to information which could allow them to deny medical coverage (Olson, 2014).

"It's going to be very important that as we move towards the future we don't set up a system where people become pressured into wearing devices to monitor their health" (Olson, 2014, para. 39)

CONCLUSIONS

THE IMPACT OF SOCIAL NETWORKS ON HEALTHCARE

Social networks are changing the way people access information and communicate online. With the growing popularity of platforms such as PatientsLikeMe, Web 2.0 is impacting healthcare as well. Proponents of using social networks in healthcare argue this will lead to more patient-controlled decision making process of healthcare. More time is spent on making medical decisions on our own than time spent at a consultation and with growing access to medical information online. Thus, patients could be misinformed. Self-medication has also becoming a growing phenomenon over the past years due to the information available online. Thus in order for Web 2.0 to impact healthcare positively, strategies are required in order to take advantage of these new technologies. This may require changes in the way healthcare, medical research, clinical trials, and doctor patient's relationships work, so that more patient control will lead to better quality of healthcare.

Websites such as PatientsLikeMe aim to achieve this by encouraging patients to share their medical information with the industry, institutions, researchers and

other patients. The company argues that information gathered directly from patients, which is now made possible through WEB 2.0 and 3.0 software, will lead to an evidence based healthcare system as the data will come directly from people who manage a personal condition, rather than from clinical trials.

An evidence-based medicine is the first and important step towards achieving the goal of patient control in the decision-making processes of healthcare. With patients receiving the biggest impact from health-care legislation, clinical trials and pharmaceutical development, by involving them in these processes, the healthcare system could “research, increase recruitment rates, and maybe even get faster cures. Just by listening.” (ENG, 2014). By doing so PatientsLikeMe believes that more and better quality data can be used in healthcare derived directly from real world patients, rather than from limited clinical trials. The use of Web 2.0 in health care will also allow patients to easily access medical information, monitor their own health, and receive support from, or provide to, support from other patients. Patients are not the only ones who benefit from this strategy. Pharmaceutical companies also stand to profit. Clinical trials continuously miss their targets due to insufficient data, misinformation or simply confusion from trial patients (ENG, 2014). By incorporating the volumes of data collected by websites like PatientsLikeMe and other WEB 2.0 applications the patient-industry partnership could ensure better products at lesser costs.

“We want patients to continue to benefit in real time from the information they share, so we’re very focused on developing patient data with more information on all diseases, as well as co-morbidities. Ultimately, we want to create a collaborative platform where pharmaceutical companies, hospitals, non-profits and, most importantly, patients themselves can work together to deliver a new level of disease understanding.” Dr. Paul Wicks

(McCluskey, 2014, para. 9)

WEB 3.0 is the next step for social networks in healthcare. It is connecting all the pieces and devices, and communities into a global data collecting machine which will provide detailed medical data in real-time supplied by a swarm of mobile devices. A health care eco-system which will evolve out of micro-contributions

creating the most accurate representations of medicine for industry, patients and government to interpret and use.

Skeptics however worry that with more transparency and ease of access to medical information online there are many risks. This could cause problems in compliance between physicians and patients about treatments. Also patients might read about experimental medication in hopes for finding treatment and self-medicating without the supervision of medical professional risking possible side effects or further harm to existing condition. Pharmaceutical companies could cause this deliberately in order to cut costs in clinical trials without holding any responsibility as patients will have tested the treatment by their own will. There are also concerns regarding privacy as well as reputation, whether physician, institution, or patient. Therefore whilst the developed of technology will allow for more remote, data driven healthcare, localized traditional healthcare delivery will still exist within a greater context of 'HEALTH 3.0.'

Therefore the most likely outcome would be a balanced system, where more and better information will facilitate transparency and better decision making within the existing localized healthcare systems. With patients becoming more educated about their medical status, social networks and new technology will help maintain patient awareness against dangers and exploitation. Healthcare may be the first industry to transform into a community eco-system of micro-contribution through WEB 3.0, leading by example for other industries to new bottom-up approach to analysis and production.

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