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Abstract

The transformative power of the Internet on all aspects of daily life, including health care, has been widely recognized. These transformations reveal opportunities realized, the promise of future advances, and the problems created by the penetration of the World Wide Web for both individuals and for society at large. Health Web Science explores the role of the Web as it drives discussions, technologies, policies, and

solutions related to health. We also examine the impact of the Web's health-related uses on the design, structure and evolution of the Web itself. The orientation of Health Web Science, compared to related research domains, motivates innovation in Web technology and better utilization of the Web for communication, collaboration, information access and sharing, remote sensing, and even remote treatment.

Dedication

This book is dedicated in memory of

James R. Brooks 1995–2014
Tristan Clark 1991–2013
Sergeant Matthew Scott Patton, 1990–2013
Eugene Landau 1950–2013
Peter T. Demos 1919–2013
Bennett L. Greenstein 1956–2009
Sylvia Statlender Luciano 1919–2007
Joseph William Luciano 1916–1985

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Foreword

As a researcher and social scientist, I have come to realize the value of varied perspectives in both discipline and disciplinarity. A researcher from the tiny country of Lebanon, I am also used to the feeling of being a foreigner amongst peers. In the spring of 2010, during the Web Science conference in Raleigh, North Carolina, this feeling was even more pronounced. I found myself amongst a vibrant community of computer scientists, hypertext gurus, and statisticians who were all gathered, like me, to discuss the impact of the World Wide Web. In chorus, I too wanted to share in its applause as a beautiful set of technologies that enabled people to produce, share, and improve information of all kinds from anywhere in the world. But, more importantly, I wanted to be clear that the Web seen from Beirut was not that same as the Web seen from Raleigh. Instead, Beirut's Web is about an emergent online platform for community building and mobilization against authoritative regimes; about cyber warfare among Middle Eastern armies; and about the transformation of traditional values of Arab societies. This was my perspective. This is what I had come to share with the Web Science community.

As I glanced around the room at that first conference, I was fortunate enough to choose a table that would reinforce my decision to attend and engage with this community. There I sat with researchers like Cathy Pope, Professor of Medical Sociology and Susan Halford, Head of Sociology and Social Policy (both at Southampton University), whom emphasized the need for multiple-perspectives in order to truly understand the Web's impact on societies, cultures, etc. The following year, in Koblenz, Germany, members of the Health Web Science Community including, Dr. Elizabeth Brooks and Dr. Joanne S.Luciano, met to push forward this specific domain. They, like me, were deeply involved in understanding the Web's influence on our everyday lives. Over the years and many more conferences later, I continue to be impressed and enlightened by the inventive and innovative work of web scientists. The Royal Society was forthcoming in 2010, when it decided to include Web Science in the 10 most important research domains for the twenty-first century.

The collective efforts of the authors of *Foundations and Trends in Health Web Science* is an enormous testament to show how the Web has changed the way we approach modern-day health issues. This is Web Science at its best, with insights into technology, society, and humanity. The various authors, spanning multiple disciplines, including clinicians and practitioners, convey a much-needed 360-degree perspective of the Web's impact on the health domain. Specifically, the monograph takes knowledge and observation to the level of personal experiences, where common languages of mixed methods can help each of us objectively to evaluate the Web's efficacy.

After reading the monograph, I felt much more informed about the challenges of Health Web Science; particularly in different parts of the world. Given my background, I was surprised to learn about the different attitudes and reactions of patients and doctors to some of the E-health services described in the monograph. Overall, it lays the foundation for a new discipline to support future medicine. Pointing to the lack of research evidence that E-Health is beneficial as a new "global thinking to improve healthcare," the authors review the relevant dynamics of contributing disciplines to Health Web Science. For instance, social science helps bridge the gap between advanced research

design and the "real world of practice." The authors show how actors and stakeholders use the Web to influence policymaking, costs strategies, and take advantage of its global impact to raise awareness on health issues. This impact follows three aspirations: efficiency of health services, dissemination of data, and improvement of access. However, the authors are cautious and state that positive externalities created by policy, technology, and development may not be so easy to obtain. Going forward, those who choose health related disciplines would need to understand enough about the multiple, different aspects to aide in their decision-making.

This monograph provides a basis for a new multidisciplinary science. It is written by scholars from multiple disciplines who worked together to make the monograph accessible from any discipline. It is full of important and interesting data and it questions our usages, our safety, and our general practices in relation to health knowledge and information.

Finally, a word of thanks to Dr. Joanne Luciano for her vision and leadership in undertaking this monograph and for being such a great person and scientist.

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Preface

The Web has quickly become a common repository for all human knowledge as well as the means for connecting people to people, globally. We access it over an ever-increasing variety of devices, including gadgets that we wear and, our very clothing. It has become so pervasive that in some cases it has become invisible, automatically connecting machines to machines and databases to databases. The kinds of connectivity and information-sharing that we take for granted in our cars — for GPS and road service — and that we use to keep track of children, pets, and prisoners, will be widely used for remote medical monitoring and treatment, with sensors as well as devices for dispensing medications embedded in our bodies. Standalone medical implants, like pace makers, will become obsolete — all such devices being remotely adjustable and fixable and instantly providing data that can be correlated with other health data. At the same time, nanotechnology is opening opportunities not only for medical diagnosis and treatment, but also for human enhancement — everything from pills that you swallow that have cameras in them to implants into the cornea that could provide night vision to soldiers in the field.

Along with the new opportunities come new challenges. Patients as well as doctors have access to an overwhelming wealth of information already. Hence the role of medical professionals is expanding and evolving. Not only must they be able to quickly access and judge data to make informed decisions, but also they need to educate and consult with patients who are also using such resources, and may, in some cases, as a result of independent Web-based research, have more information than the medical professional. This collaboration that includes patients and their values, which differ by culture and by person, is a new paradigm in western medicine and in personal health.

So, as all of western medicine moves from diagnosing and treating the mythical "average" patient to dealing with the individual as an individual and as a collaborator, with personally tailored treatment plans and DNA-specific medications, the medical community and the health of all of humanity will depend increasingly on web-based data, devices, collaboration, and applications.

In this fast-paced environment of Web-based medical innovation and collaboration, Web Science has emerged as a new multidisciplinary field whose charter is to study the Web in all of its aspects, including engineering, governance, and society.* It is the goal of this book to explore these concepts for a wide-ranging set of academics, engineers, medical doctors, and practioners in any of the relevant fields.

We begin our exploration with a brief discussion regarding the evolution of the Web from a simple vehicle for communication to a far more complex system that enables qualities like interactivity, immediacy, mobility, and web-scale collaboration. We divide its evolution into three iterations, which signify shifts in infrastructure and use. These include: the "Web of Documents", the "Social Web", and the "Web of Linked Data". Today, the Web has become a part of daily life, not only among the richest societies, but also in industrializing countries. Even

* The impetus to formally name Health Web Science as distinct research field, with a charter to study the aspects of the Web related to health and to recognize health as a driver for Web development, arose from a workshop on Health Web Science held in conjunction with the Third International Conference on Web Science in Koblenz, Germany, in June 2011. This dialog continued at the Second Health Web Science Workshop in Evanston, Illinois 2012 and again at the Web Science conference held in Paris 2013.

in areas where computers are scarce, mobile devices have penetrated, allowing the Web to be accessed through mobile apps. The phenomena of Web Science is the realization that the access to the Web goes beyond retrieving information from a remote site, or using it as to make a video call, or writing a blog -it is something different and something greater. When we interact with the Web, i.e., retrieve information from, communicate via, or change the Web, by modifying the architecture or content, we furnish the Web with the capability to change us.

While use of the Web has become nearly ubiquitous, adoption of the Web as a driver of health, healthcare, and health research has been relatively slow. Researchers note that, while health related technologies have long existed, they traditionally take the form of closed health informatics systems that were predominantly focused on health administration rather than how health informatics systems could be utilized to improve health outcomes. Concerns regarding privacy, authenticity and design limitations have also stalled the adoption of newer health-outcome focused applications.

Yet, as the Web continues to mature, so too does the health industry. The Journal of Medical Internet Research, founded in 1999, publishes on "all aspects of research, information and communication in healthcare using Internet and Intranet-related technologies." While older and broader in scope, a more recent journal, the Journal of Biomedical Semantics, founded in 2010, publishes papers on issues of semantic enrichment and semantic processing in the biomedical domain. These include infrastructure for biomedical semantics and semantic mining, annotation, and analysis.

Perhaps the defining feature of Web Science is the study of the Web's unanticipated emergent characteristics. In order to improve healthcare through the application of Web Science, we must first understand Web Science, and then explore how the novel technologies and human-behaviors emerging from Web Science relate to the achievement of better health outcomes. To do so, we need to integrate the collective wisdom and perspectives of multiple disciplines. Such integrated knowledge will enable the development of prescriptive interventions that are of a Web nature and on a Web scale. The field of Health Web Science aims to accomplish this goal. It concerns itself with

how individuals (professionals, patients, communities) and machines co-create the virtual environment within which they live.

Scholars of Health Web Science, spanning many distinct disciplines, note the emergent properties of the Web that are significant to human health, health care administration, health care delivery, health information acquisition and delivery, and health research. These individual observations, studies, and scientific breakthroughs are subsequently studied in their aggregate in order to understand their heuristic value. Framing these activities as a new discipline facilitates the necessary collaborations that will enable us to observe and assess the impact of the Web-based human-computer-community interaction on human health.

Understanding this mutual influence between technology and people will help us better prepare for a variety of immanent and significant challenges. For example, one key goal of Health Web Science is to support the world's aging population, and address the associated increase in chronic illness (Yach 2004, Holman 2005) and the consequent costs of healthcare that will render current models of health care delivery largely unsustainable. To address these challenges, more effective methods of healthcare delivery and intervention programs are needed. Thus there is the motivation to utilize the Web to both improve health, as well as to decrease its delivery cost. This cannot happen without research into the benefits and pitfalls of the potential capabilities of the Web in the human-computer-societal ecosystem. Moreover, so as to not waste existing infrastructure, we need to understand how Web-based technologies can complement and improve traditional models of healthcare delivery. As a result of formalizing, and thus establishing the discipline of Health Web Science, we hope to unify and coordinate our efforts to provide the data and evidence that will allow all societies to become better informed and more empowered; to enhance participants' understanding not just of health care options, but also the *politics* behind healthcare delivery and thereby make more and better informed decisions towards a healthier human existence. Thus Health Web Science holds important promise both for our rapidly changing health care system and for the consumers who utilize it.

The Web has also revealed itself to be a powerful motivational tool. Health Web Science, therefore, studies and leverages this human

response to the technology in an effort to improve patient outcomes. For example, one way for societies to improve their health is to move from a reactive (illness) model -where individuals only take an interest in their health when they are ill and respond to directives issued from health care professionals- to a proactive (wellness) model. In a preventive, personalized, participatory, and predictive proactive model, individuals take responsibility for their wellbeing and health and are therefore not only informed but also part of the discussion and decision-making process about their health care (Kahana & Kahana 2003, 2007). Incentives for proactive behavior can be driven by the very characteristics of the Web that have led to its global success, including immediacy, mobility, multimedia, search, customization/personalization, and time shifting, the capability to consume media at a time you choose* (Stein, 2011; Baur, Deering and Hsu, 2001, 356; Duffy and Thorson, 2009, 107; Jimison et al., 2008, 1; Rice, 2001, 35; Street and Rimal, 1997, 3; Street and Piziak, 2001, 290; Walther, Gay and Hancock, 2005, 633). Beyond the successful intersection of the Web and Healthcare in a variety of initiatives (many of which are discussed and examined in this book) the Web has, nevertheless, an as-yet unrealized capability to enable and empower individuals and communities to adopt activities that promote health and improve healthcare.

Health Web Science also seeks to inform the development of the Web itself. For example, many health-related Web initiatives in the past have assumed that if you build a useful resource, people will take advantage of it. This has not always been the case, and worse, in some cases the use of the Web resource has had negative consequences. Thus we must study the incentives and motivations of people to utilize Web resources, in order to achieve the active participation of all participants in the Health Care continuum, but moreover, we must also recognize and understand the potential of the Web to do harm, and similarly study the motivations, mal-incentives or design-flaws that lead to negative outcomes. Such directed research will allow us to identify factors that maximize the benefits while limiting the perils. For this reason, we

* Prior to the Web, VCRs and DVRs, one could only view (or listen) to a broadcast program at the time it was being aired. Time-shifting technologies enable viewing at a later more convenient time.

have devoted crosscutting sections of the book to discuss the issues of individual privacy and health data on the web and the motivations of policymakers and interest groups in calling for the utilization of web technology in health.

In the closing chapters of this monograph we attempt to identify future research questions as a means to better understand future directions for growth within the Health Web Science discipline. For example, we will raise questions such as, which on-line communities have had an impact on health outcomes? Which online communities have caused harm? What are the factors that make the difference? Does access to health data actually improve one's health or hurt it because it falls in the wrong hands? How do health behaviors and Web-based communities differ across cultures? What factors are relevant when accessing the Web for health care across different demographics such as age, gender, belief systems, life experiences, and religious or sexual preference? Can the Web be used to help us find out about health issues or outbreaks before they happen? What are the limits of the impact of the Web on health issues, and can knowing them better help us prepare for and accept them? We explore the questions raised primarily in the context of one or the other of two divergent healthcare systems in developed countries, namely those of the US and the UK. Indeed the co-authors include scientists from both of those regions. In this book we alternatively refer to challenges and opportunities posed by Health Web Science as they interact with or apply to cultural, organizational and demographic features of these environments. We recognize that other regions in the world including those in developing countries may face parallel or divergent challenges and opportunities through the Web. Indeed, the Web can be an important facilitator of remote medicine over the mobile web. It is our hope that the insights offered by this volume will stimulate further research relevant to for diverse regions beyond those included here.

The contributors to this monograph come from a wide variety of disciplinary backgrounds, with experience in health science, the formal sciences, and social science. There is a bias towards describing Health Web Science through the lens of people working in the USA and UK; assumptions and results do not always cross socio-economic and

cultural borders. Some areas of the text will resonate more readily with doctors, other areas with social scientists, and still others with data scientists and Web scientists. The "diversity of voice" within this treatise is intended and unavoidable, as it reflects and embraces the multidisciplinary, co-production philosophy that characterizes the nascent discipline of Health Web Science. We have, however, endeavored, and hopefully succeeded, to make all areas of the book accessible to anybody with an interest in this new discipline, from those coming to the topic for the first time to those more experienced this space.

1

Introduction to Health Web Science

Recently, many Web researchers and developers are beginning to talk of a Web not of linked documents, but of linked *data*, sometimes called Web 3.0 or the Semantic Web, in which the data within Web pages can now be "read" and "understood" by machines (W3C 2001). An alternative to the Semantic Web or Linked Data definition of Web 3.0 is presented by the theory of autonomous agents. Conrad Wolfram remarks that this stage of development of the Web is one in which "the computer is generating new information". The computer is a content-creator "producing new results in real time, responding to a question" [123]. Independently of what one chooses to call it... Web applications that approach an emergent technology only allow for new insights in data and information and not necessarily completely new data (Wolfram) Twenty years ago, many of these developments could not have been predicted; they evolved from and with our interactions with the technology.

As the Web has undergone these transformations from "Web 1.0" to the more interactive "Web 2.0" and increasingly to the intricately linked data of "Web 3.0", corresponding terms have appeared in the discussion

of health and medicine in relation to the Web. Terms such as "health 2.0" and "medicine 2.0" have recently appeared in the literature (Van De Belt 2010) to suggest that Web technologies may support and enable interaction and the creation of user generated content relevant to health care. Medicine 2.0 has been used to denote the Social Web in health, medicine, and biomedical research (Medicine 2.0 Congress 2012). There is no general consensus as to these definitions, and definitions are influenced by the different stakeholders' agendas of which there are many [204]. Nevertheless, there seems to be agreement that using the suffix 2.0 denotes the ability of the technology to provide interaction and allow the creation of user generated content, which is the hallmark of Medicine 2.0. The lack of a specific definition reflects in part that the technology, and how we use it, is dynamic and evolving, and this in turn highlights the requirement for a multidisciplinary approach towards understanding the impact of this technology on healthcare, communities, individuals and society as a whole.

1.1 What is Web Science?

Web science is the study of the World Wide Web and its impact on society and technology [28]. Web Science seeks to understand the multifaceted nature of the Web and its development as a key communicational and representational system that enables information systems to be decentralized. It further studies how to utilize that knowledge to advance and engineer the Web itself. It includes the study of those interfaces that emerge at the boundaries of the Web and the individual, and extends to society, policy, and government issues. Current central engineering issues in Web Science include the development and evolution of the Semantic Web, Web services, and peer-to-peer networks, where no dedicated server is involved. Web Science analytic research has focused mostly on the Web's topology, i.e., its graph-like structures, and what can be learned about individuals, organizations, and societies from these networks. However, the Web has emerged as a social technology, which raises further questions about Web use, policies, and governance.

1.2 What is Health Web Science?

Health Web Science is Web Science with a health remit -to understand how the web shapes and is shaped by health related activities. In so many words: Health Web Science is not only the application of Web Sciences to health but the study of emergent properties from the combination of Health Sciences and Web Sciences. It therefore studies the Web (and technologies that use the Internet), their emergent properties, and how these are being and can be harnessed or held in check, and by whom, to benefit society in the area of human health. It also concerns itself with understanding how people (health professionals, patients, communities) co-create and engage with the emergent health ecosystem within which they live. Furthermore, it studies how the Web can be engineered or developed in relation to health, medicine and healthcare.

Health Web Science requires cooperation among disciplines, because it is not only interrogating a social and technological ecosystem, but also designing it. This involves a range of actors such as health professionals, lay people, Web designers, computer scientists, quantitative and qualitative researchers, health economists, behavioral scientists, social scientists, ethicists, lawyers, policy makers, educators, and government organizations. Each of these constituencies brings different insights to the field that ultimately coalesces into a meaningful gestalt that is referred to as Web Science.

1.3 The Heath Web Science Space

The current model for delivering health care is unsustainable [201]. Given that the Web has emerged as a daily part of life for much of the western world, it may offer a route to finding solutions that help to mitigate rising health care costs and help make healthcare sustainable. Commerce, education, and entertainment organizations that have embraced the potential of the Web have seen revolutionary benefits, with the penetration of e-commerce continuing to grow between 15–22% per year for the past six years (ComScore 2012).

Health care systems need a paradigm shift in their health care models, i.e., a move from a reactive (illness) model to a proactive (wellness) model of health care delivery [67]. The Web may afford opportunities to facilitate such changes. It may act as a conduit for creating an environment in which individuals and communities are encouraged to take more personal responsibility for their own health and treatment through empowerment, co-creation and co-production. In addition, there are expectations that remote monitoring and management of a wide variety of health conditions can be achieved using this technology. Because of this potential of the Web to change how health care can be delivered, there is increasing interest in eHealth, Health/Medicine 2.0 and the emerging discipline of Health Web Science to evaluate the impact of the Web on health maintenance and on healthcare delivery.

Airlines, banking, and other industries have successfully integrated information technology (IT) into the routine running of their businesses. Other than for administrative tasks, healthcare has been a "late adopter" of information technology, despite arguments that IT adoption would improve the quality, safety, and efficiency of care. Hence a different story can be told, with claims that IT has over-promised and under delivered [193]. This has led to recognition that complexities of healthcare data and information create a greater challenge for IT than for most other sectors. Beyond complexity, additional barriers to adoption include: cost, and institutional and individual change required within both the complex and fragile medical systems, as well as with the busy medical practitioners. Critics have also cited lack of an evidence for the efficacy of healthcare delivery via the Web, while proponents of the technology argue that a paradigm shift in the methodological approach is required to make this determination, and to the early adopters, the revolution is well underway.

Currently we are in an expansive stage where we continue to see an increasing number of calls for additional technology to support improvement and change in healthcare. In the US, the President's Council of Advisors on Science and Technology (PCAST) generated a report (PCAST 2010) on "Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: the Path

Forward". This, and reports like it highlight the potential for and need for improved health informatics support, also providing additional motivation for study and development for health web science. With increasing financial incentives such as "meaningful use"[1] providing reimbursement incentives for health care providers to become more effective users of electronic health information, the opportunities are growing as more organizations are seeking help in understanding and using electronic health information effectively. In addition to provider meaningful use incentives, we are currently seeing a growth in financial incentives aimed at the developer communities, (often taking the form?) these take the form of application and data challenges and innovation awards.[2,3]

Finally, with respect to academic health research, there is a need for Health Web Science to define approaches to data and knowledge management for health data, with a particular eye to issues of privacy and law; to explore how self-organizing groups of citizens on the Web can be studied to gain insights into their health needs and behaviors; to define ways of discovering and integrating data from global health resources, delivering the right information to the hands of the researcher at the moment they require it, in a manner similar to how personalized medicine intends bring the right information, about the right patient, at the right time, to the clinician, and to enable individuals to utilize the web and it's resources for health information, solutions, maintenance, and what to do to maintain wellness through the life cycle.

In summary, there is a compelling argument for health web science to describe the tools needed to enable, empower, and evaluate web-based healthcare. If the science shows web based health care is efficacious then the consequences will be profound and the more we know about how the web works in the health sphere, the better able we will be to utilize it as a resource.

[1] An explanation of the concept of Meaningful Use can be found at http://www.medicity.com/meaningful-use-101.html.
[2] http://www.iom.edu/Activities/PublicHealth/HealthData/2012-JUN-05.aspx
[3] http://challenge.gov/search?cat=25

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