**Health Sandpit Report:  
 From Paternalism to Libertarianism**

# Background

This report has been shaped by issues highlighted in presentations by NHS Direct, NICE and Simply Health during the Web Science DTC industry week in December 2012. The central theme that emerged is a view of the Web as advancing a libertarian model of healthcare as a shift from the traditional paternalistic approach. Paternalism is embedded within the traditional model of healthcare where clinicians and healthcare professionals were credited with the knowledge and expertise to determine the best choice for the patient, regardless of the patient's will.

This shift in approach has been facilitated by the technical possibilities afforded by the Web. Patients are progressively informed and can be paramount in the decision making process, basing their choices on knowledge obtained from online resources. Anecdotal views of health issues appear to dominate the Web and support this process. Understanding why such information is regarded as trustworthy and influential is just one of many challenges posed to Web scientists who are concerned about the future of healthcare and the Web. This report further details other emergent areas of concern and the contribution that could be made by Web science.

# Research Agenda

Several sub-themes were highlighted under the umbrella of paternalism versus libertarianism. Research questions for each of these sub-themes are posed to encourage further investigation into these areas.

## Choice and Governance

One of the most observable features of the Web is the expansion of 'choice'. For example, the increased availability of health information and medication for purchase from varying sources online has presented choices that may not have been presented in a medical consultation. This can potentially allow for a subversion of enduring medical discourse. How does the healthcare system respond to a dramatic increase in choice? Is there a need for such regulatory frameworks to address this explosion of online health-related content that results in an expansion of choice?

Paternalistic governance of traditional medicine is challenged by the idea of libertarianism with the notion of the ‘expert’ patient. These individuals have the freedom to navigate both complementary and contested spaces on the Web. This may enhance knowledge and information that is provided by a practitioner, or provide a basis for the individual to explore the potential for alternative health options. Therefore, does the Web undermine a paternalistic healthcare model? Would the expert patient be an asset to the health service? Alternatively, are patients who are informed by Web sources likely to begin disregarding advice from 'traditional' voices of medical authority?

## Support

Many Web platforms (e.g., social media sites) have often become new venues for support. Patients can anonymously benefit from freely sharing and learning from each other's health-related experiences and knowledge about illness, without any of the associated embarrassment that can be felt when seeking help offline. It is important to further explore how Web features influence interaction within online support groups. What new support structures does the Web facilitate? Can traditional expertise become embedded in emergent peer support networks?

It has been argued that anecdotes from similar patients hold significant power as these are strongly considered by individuals when making health decisions. This 'expertise through experience' raises important questions about the Web's impact on health information. Furthermore, it questions the extent to which medical expertise is becoming embedded in these peer support networks, as opposed to being supplanted by anecdotal evidence that may go against the medically accepted advice.

## Expertise

The paternalistic healthcare view, where patients are passive and doctors diagnose and treat them, is based upon the understanding that doctors have the expertise and patients do not. The increased availability to this specialist knowledge via the Web is challenging the authority in the doctor-patient relationship. This increases the power that patients have, such as the power to retrieve a second opinion, obtain a referral to a specialist or negotiate treatment. However, the doctor still functions as a gatekeeper to treatment. Do these changes impact the relationship between doctor and patient? How does the fact that the Web provides this information empower patients?

## Dissemination of Information

The Web provides many platforms for the dissemination of health information in several formats and from countless sources. Though this opportunity promises to satisfy the informational needs of citizens for healthcare, it also present challenges when attempting to unlock its potential. Citizens must overcome several barriers including finding the requisite information from the Web's enormous collection, evaluating its quality and also deciphering the technical language sometimes used. What skills do individuals need to navigate this Web environment? How can these skills be delivered or developed?

## Delivery

e-Monitoring devices are giving patients more control over how they manage their conditions without having to regularly attend a medical facility for testing or remain there for close monitoring. Understanding how the Web supports or disrupts the facilitation of healthcare delivery is important. For example, though more convenient and efficient, patient satisfaction with these tools and the social implications of using them may not be positive. These tools may reduce the amount of physical contact between patients and practitioners, as there is no need to see the patient unless the e-Monitoring device reveals negative results. Not all patients might be satisfied with this arrangement. Given the potential for these types of technologies, it is imperative to consider whether delivery of these services will support or disrupt health services.

## Responsibility

The ideological shift to an individualised approach to healthcare is not a new phenomenon and has been prevalent in neo-liberal politics for decades. The Web provides a major step towards individuals taking more responsibility for their healthcare (e.g. reflexively navigating various spaces to consider health pathways). However, there arise questions of responsibility. If there is a shift towards individualisation of health, is it still the responsibility of health professionals if the patient encounters a problem? Where does the liability lie? Does a system of distribution need to be developed regarding responsibility? If there is a move to this model, how do we support people to take responsibility for their own healthcare?

# What Can Web Science Contribute?

Given its focus on interdisciplinarity, Web science is dedicated to delivering impactful research into these sub-themes resulting in a significant contribution being made to the future of health. Perhaps we find that patients obtaining misinformation online or self-medicating and being at risk is less of a problem than the authorities envisage. There is a pressing need to identify what is and is not working, and to proceed with finding ways to develop a more pro-human Web that supports the former and effectively addresses the latter. Similar to what it has done and continues to do in other industries (e.g., cyber security), Web science can develop effective ways to study and deliver actionable insight into complicated issues related to health on the Web. Perhaps observing and obtaining the perspective of the patient (usually underrepresented in healthcare research) via joint projects with the Web Observatory. In addition, as information is being readily sought without professional input, new methodological approaches must be considered in trying to determine the availability of credible information online.