

Emerging Ethical Issues in Digital Health Information

ICANN, Health Information, and the Dot-Health Top-Level Domain

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Abstract: The problems of poor or biased information and of misleading health and well-being advice on the Internet have been extensively documented. The recent decision by the Internet Corporation for Assigned Names and Numbers to authorize a large number of new generic, top-level domains, including some with a clear connection to health or health-care, presents an opportunity to bring some order to this chaotic situation. In the case of the most general of these domains, “.health,” experts advance a compelling argument in favor of some degree of content oversight and control. On the opposing side, advocates for an unrestricted and open Internet counter that this taken-for-granted principle is too valuable to be compromised, and that, once lost, it may never be recovered. We advance and provide evidence for a proposal to bridge the credibility gap in online health information by providing provenance information for websites in the .health domain.

Keywords: Internet Corporation for Assigned Names and Numbers (ICANN); generic; top-level domain (gTLD); Internet openness; health information; information quality

Introduction

People turn to the Internet for advice on healthcare issues, sometimes second-guessing their doctor, to the extent that the phrase “Dr. Google” has become common currency.^{1,2,3,4,5,6} Yet it is also evident that much health and well-being advice on the Net is either bogus or biased. The argument can thus be made that there should be a safe, top-level Internet domain name space for reliable health information, where it would not be possible to post fraudulent claims of cures or ill-conceived, dogmatic advice on health that lacked the appropriate scientific basis for use by patients and consumers. A significant debate has been taking place around this serious public interest issue, occasioned by a major recent development.

The reason for the debate is a decision by the Internet Corporation for Assigned Names and Numbers (ICANN) to expand the range of global, or generic, top-level domains (gTLDs), that is, the highest level of the domain name space (DNS) or, more simply, everything after the last “dot” in a web address. ICANN is described on its own website as “a private sector, non-profit corporation with technical management responsibilities for the Internet’s domain name and address system.” It appears largely self-referential, governed by a complex web of quasi-independent bodies and committees concerned with different aspects of Internet governance. Its principal concern is the functioning of the DNS; it is currently focusing on the allocation of thousands of new gTLD names to organizations that bid to manage them in its new program to allow virtually unlimited expansion of the Internet. Allocation, in the event there is more than one applicant for a gTLD “string”

or name, is largely by auction to the highest qualified bidder but is termed “delegation,” a word far removed from the commercial competition that underlies the process. Importantly, ICANN is currently proposing to allocate or has already awarded about a dozen health-related gTLDs, including “.doctor,” “.healthcare,” “.medical,” “.hospital,” and others. For some of these, a website using the relevant second-level domain (i.e., the space directly below the top-level domain) would have to be owned by an appropriately qualified person or organization: to be “someone.doctor,” someone would have to show that he or she is accredited as a physician (compare “.edu” for academic institutions). However, this principle has not been extended to all domains, the most notable exception being the proposed management of the gTLD “.health.”

Health Information Seeking on the Internet

There have been numerous studies of health and well-being information sharing and information seeking on the Internet. Whether this is due to the popular focus on lifestyle and consumer health, to greater patient activism, or to the increasing emphasis by governments to persuade citizens to take more responsibility for their own health is not clear; but there has been a considerable flourishing of publications in this field. Our literature search for publications on the topic of “Internet health information” has located reviews, research papers, and semipopular articles both in the literature of computing/informatics and related disciplines and in medical/healthcare journals. We have found early papers both extolling the promise of the Internet and lamenting the quality of health information then available on the Net. However, we have focused our brief analysis on publications since 2010. We have excluded articles relating to the sale of drugs on the Internet, to mobile or ubiquitous health (m-health), to the pathologies of Internet use (e.g., addiction to Internet use in general or to a particular type of content, such as porn, online dating, or online sales), or “netiquette”: advice on good manners on the Internet. This review of the literature makes no pretense to being exhaustive or complete but does provide some evidence of the importance of the Internet in health information-seeking and information-sharing behavior. It should be noted that all references are offered merely as exemplars of the kind of article or review we are discussing, not necessarily as the definitive publication on any given topic.

The papers and reviews we have identified vary widely in their motivation, scope, focus, and professional authorship. For example, some authors focus on particular constituencies^{7,8} identified by disease, by country or region, by language, by demographic (e.g., foreign graduate students or parents of children in urban environments), or by gender (e.g., women in general or African American women in particular). Some articles focus on the reasons for seeking information, such as risk reduction through healthy living or recent diagnosis of a particular disease, or, most strikingly, on the patients’ sense of empowerment in the face of medical authority or against a background of deprivation.^{9,10} Other articles are oriented toward the occasion when patients access the Internet, for example, a self-motivated search for a continuing source of information following consultation with a provider, or because the provider has given an information prescription to the patient—that is, a physician-directed, Internet-based health education intervention, often mediated by a medical librarian.^{11,12}

There is a substantial literature on methodological issues relating to health information on the Internet, including analyses of information-seeking patterns,^{13,14,15} health literacy standards and education,^{16,17} presentation and communication styles,^{18,19} the impacts of innovation,^{20,21} trust and credence placed on websites and their provenance or content,^{22,23,24} and the usability and design aspects of health websites and forums.²⁵ We have also found evidence that both medical literature and the education of physicians are being influenced by online health information^{26,27} and that the methodologies for the construction and presentation of health information on the Net, and the methods of evaluation of such information, are themselves attracting the attention of researchers. There is a marked sophistication in recent studies, which often utilize benchmarked scales²⁸ (such as Silberg,²⁹ DISCERN,^{30,31} and LIDA³²) to evaluate websites that contain healthcare information.

Ethical Dimensions

Healthcare economists think in terms of the interplay and tradeoffs in three key dimensions: cost, quality, and access.³³ Although it does not provide a perfect analogy, it may be helpful to think of healthcare and well-being information and advice on the Internet in similar terms. Does this information cost something—is it behind a “paywall”? If it is free, might it be of inferior quality or biased? Or if its quality is high, does it come at a price of less accessibility—it is written for a specialist readership with a high degree of medical literacy, or is statistical sophistication required to understand its conclusions? Or if it is both good and accessible, do you have to pay a moral price—be subjected to advertising, because that is the only source of revenue for this website? It is good to be aware of these considerations when discussing provision of healthcare information and advice on the Net.

Access to the Internet and the accessibility of its content at first appear only indirectly relevant to our main concern. But, to return to health economics for a moment, access is often broken down into the “five a’s,” each of which may be seen as a dimension of interpretation of the qualities of information: *affordability* speaks to the possible cost of the information; *availability* and *accessibility* speak to the lengths one may have to go to find and access Internet advice, both physically, in terms of ownership, connectivity, and travel, and virtually, in terms of search time and the method of search (e.g., use of search engines, web databases, blogs, social media, etc.); *accommodation* and *acceptability* suggest a deeper challenge: to what extent must the information and advice provided be sensitive to religious or political beliefs, and how far must it go to conform to cultural norms?

In ethical terms, healthcare and well-being information on the Internet should arguably be subject both to the principles of bioethics and to those of information ethics. We are at all times concerned with the kind and quality of information and advice offered—its authenticity, its accuracy, its clarity, its impartiality, and its rootedness in up-to-date evidence. Just as importantly, we are also concerned with who is providing that information and advice, and with what motivations and credentials that provider might have. At its simplest, will the information and advice provided be beneficial and safe? Is the source complete and clear about its own limitations, so that the user can judge whether to accept or reject the information provided?

Looking to a religious source, in which we may expect to find a degree of sensitivity, the Pontifical Council for Social Communications at the Vatican offers this reflection in its document “Ethics in Internet”:

Standing alongside issues that have to do with freedom of expression, the integrity and accuracy of news, and the sharing of ideas and information, is another set of concerns generated by libertarianism. The ideology of radical libertarianism is both mistaken and harmful—not least, to legitimate free expression in the service of truth. The error lies in exalting freedom “to such an extent that it becomes an absolute, which would then be the source of values. . . . In this way the inescapable claims of truth disappear, yielding their place to a criterion of sincerity, authenticity and ‘being at peace with oneself’” [Pope John Paul]. There is no room for authentic community, the common good, and solidarity in this way of thinking.³⁴

But having extolled truthfulness in relation to the public sphere, the document appears to stop short of demanding truthfulness in matters that personally affect an individual, such as one’s health. The extension to health information, one imagines, shifts the burden for validation and verification of any item of information to the recipient, and even that by the lights of his or her “authentic community.”

By contrast, turning to information ethics, the focus is entirely on what Floridi³⁵ calls “the infosphere,” whose features are classified under (1) “modal properties,” which reflect the logical and practical possibility and actual existence of (some) information; (2) “humanistic properties,” which address the extent to which information persists, hangs together, is authentic and reliable, is confidential and secure, and so on—the qualities that information system designers most often associate with information in their systems; (3) “illuministic properties,” which cover the availability, interconnectedness, and communicability of information—the qualities prized by communication systems designers, perhaps; and (4) “constructionist properties,” which speak to information’s potential to be correct, to be formally representable, to be irredundant, and to be updated and corrected when wrong. These criteria should prove useful in a deep analysis of health information on the Internet. Considering these different qualities, we may distinguish between and explore different types of information according to their source: patients writing for fellow patients, physicians and other professional providers writing for patients, hospitals and health systems seeking to attract patients, pharmaceutical companies advertising their drugs, or academia or the government offering advice. We would be able to discuss technical aspects, but they appear to offer little opportunity to judge the information provided from the point of view of any effect on its recipient: is it deontic, normative, prescriptive, or exhortative?

Floridi formulates four “moral laws” based on his classification, three concerned with the negative aspects of this balance sheet and one with the positive: the first three demand that entropy (1) must not be created, (2) must be prevented, and (3) must be removed from the infosphere. The fourth law adds that *information welfare ought to be promoted by extending (information quantity), improving (information quality), and enriching (information variety) the infosphere*. We emphasize that

information welfare—and we must presume here that we are speaking of human welfare—is predicated on the extension, improvement, and enrichment of the infosphere itself. This seems to us to abstract too much from human needs and desires and from the construction of the human.

Looking to a somewhat more recent source, in their introduction to the special issue of the *International Review of Information Ethics* on information technology in healthcare,³⁶ the editors lay a broad foundation, introducing questions on the appropriate uses and appropriate users of health information systems, their benefits and risks, and their impact on human relationships and on decision-making. The editors observe: “Perhaps most fundamentally: How does (and will) information technology transform the medical construction of the human body and disease?”³⁷ This is indeed insightful, but it is perhaps also indicative of the diaphanous nature, so to speak, of the web of healthcare and well-being information that none of their contributors tackles the question of how patients construe their own condition and how information provided to them by an apparently disinterested network, rather than by a physician, may condition that process.

This absence is apparent in a preeminent resource on the public discussion of biomedical ethical issues, the Hastings Center’s briefing guide.³⁸ It is as though this information is only perceived in our peripheral vision, not by deliberate focus or critical faculty. We shall have met our goal in this respect if we have succeeded in making the link from these informational qualities to the person using the Internet and thus asserting a degree of moral obligation on the provider of health-care information on the Net.

A more recent discussion of ethical dimensions of online health information attempts to define and harmonize the evolving concepts of e-health and e-health ethics.³⁹ This includes a working definition of e-health ethics that seeks to evaluate the impact of digital technology on patient-physician interactions and that largely focuses on contemporary e-health topics such as the online practice of medicine, informed consent, privacy, and health equity.⁴⁰ These efforts have also been accompanied by development of an e-health ethics code that focuses on the establishment of the basic principles of candor, honesty, privacy, quality, informed consent, professional standards, and responsible partnerships among websites, in the rapidly growing and evolving digital health space.⁴¹

Internet Governance

Laura DeNardis, author of two definitive accounts of Internet governance,^{42,43} uses the term “multistakeholderism” to describe the Internet’s governance paradigm; that is to say, at least in theory, she points out that there are many loci of power, many points of influence, and many routes to decisionmaking concerning the functioning of the many layers of the Internet, from physical infrastructure to content. Certainly, to an outsider, it is a very complex web indeed, a web of private companies, governments, international “quangos,” technical design bodies, advisory committees, and nominees, whose accountability appears to be highly mediated and, at best, rather limited. Moreover, as technology and political pressures change, so does this virtual web of influence and governance. Impacting decisions appears to require either enormous influence or surgical precision in the choice, locus, and timing of intervention. It is critical to note in our present discussion that although the Internet is generally viewed as lacking any centralized governance,

composed as it is of largely independent and autonomous networks, the one exception is the space that concerns us: the Internet namespace.

Recent controversies provide a backdrop against which to project and assess the relatively narrow issue of expansion of gTLDs. On a global scale, these controversies include surveillance; content censorship and outages of the Internet infrastructure in the service of political ends; cyberattacks such as Stuxnet and GhostNet; calls by politicians, notably U.S. Secretary of State Hillary Rodham Clinton, for U.S. companies not to collude in surveillance through or censorship of the Internet, followed by what has been described as “the cognitive dissonance” of revelations of surveillance through the Internet, for example, by Wikileaks and Edward Snowden; Europe’s “right to be forgotten”; the yet-to-be-fully-explored risks and challenges of the “deep Web”; and even the apparently misunderstood case of “Internet neutrality”: these are the shadows that dim the hope and cloud the rhetoric of the liberatory Internet and partly explain, partly confound the U.S. government’s decision—at this particular moment—to bring some sort of conclusion to the long argument about its controlling interest in ICANN that is now undergoing significant change.^{44,45,46} The expansion of gTLDs impacts this confusion and discourse regarding Internet governance in a number of ways. ICANN needs to continue to finance operations, and the new gTLDs will be a rich source of income. Conversely, those who are concerned with the fragmentation of the Internet recognize the opportunity for innovation but also perceive a threat in the largely uncontrolled proliferation of domains.

Dr. DeNardis is a frequent speaker on Internet governance. To appreciate the argument she has sought to confront, a useful starting point is the dean’s seminar⁴⁷ at the School of International and Public Affairs at Columbia University, on April 14, 2014. During this seminar her plea not to forget the virtues of a single Internet was all but drowned out by the readiness of her fellow panelists to throw it all open to competitive expansion and “let there be many internets,” if that is where creative competition leads.

It is in this context, perhaps, that one must hear her concern regarding attempts to control the content of the Internet. She expressed this view eloquently at a panel discussion in 2013:

It’s important to view the Internet as we view other enormous collective action problems that are of a global scale, such as environment issues, such as global security, such as human rights, where no one culture, no one nation acting alone, can have governance or affect the entire structure, but that the local actions of cultures, entities, or governments can affect the whole, so it’s a collective action problem.

The final point I want to make is about interoperability, openness, and universality of the Internet. It’s very easy to take infrastructure for granted. . . . It’s an amazing thing that’s happened, to have interoperability and to have open standards that make all this available, and to have a universal network, and this is not something we should take for granted.

I think that there are two trends that are problematic in this regard, one is the turn to infrastructure for content control. We see this time and time again, whether “graduated response,” “three strikes” kinds of laws that enforce intellectual property rights that can interfere with infrastructure, or see *the turn to the domain name system for content enforcement in a variety of ways* [authors’ emphasis]. I believe these trends, particularly the use of

the domain name system for content enforcement, can take us away from the universality and the interoperability and can eventually end up fragmenting the Internet.⁴⁸

Dr. DeNardis goes on to cite a further danger in cloud computing and e-health systems that are trending away from interoperability. At the 2014 panel mentioned previously, she also cites the political dimension of gTLD control: “Who should authorize new top-level domains? Should we allow .xxx? Should we allow .gay, when Saudi Arabia has protested that? Should we allow .wine, and who has control over that?”⁴⁹

There is no doubt that these views are held for sound reasons and with deep conviction. Dr. DeNardis has also discussed them in the less politicized forum of an academic journal.⁵⁰ We have quoted extensively from her contributions so that we can be absolutely clear about what those among us who are concerned about the content of health-related websites are counterposing. Direct control of the content of websites, in our view, is neither feasible nor desirable. This is not about controlling what people think and say, nor is it about a “nanny state” not allowing its “children” to go astray. However, the increasingly heated debate concerning Internet governance in the wake of the problems outlined previously, and the decision of the U.S. government to partially free ICANN from its direct control, should not be allowed to obscure issues of an apparently more parochial concern, such as those of the recognized human right to health and well-being, including access to health information with integrity. As governments turn increasingly to patients to look after themselves, as developing countries try to jump-start their health programs, and as patients and citizens in general seek to take control of their own well-being, providing a means to underwrite the disinterestedness, the authenticity, the veracity, and the currency of health information on the Internet will be seen to be of increasing importance.

Dot Health

What exactly is it that concerns us and many others? The current health Internet debate has been misunderstood and misconstrued on many occasions.^{51,52} One of the earliest was when concerns were expressed about the content of DrKoop.com, the website of the former surgeon general, C. Everett Koop. Critical review of the site content revealed that many of the private care listings, medicinal recommendations, and medical trial referrals were thinly disguised advertisements. It is easy to see how objection to this may be misconstrued as a wish to control content. However, a means of evaluating the content through provenance information neither patronizes the user nor imposes undue controls on the provider.

Most controversial among the new gTLDs is the domain .health, which, as things stand, has been awarded prior to auction through a private settlement in September 2014 to one of three remaining commercially oriented bidders, all of whom seem to have little or no track record or expertise in healthcare, or any commitment to public health⁵³. Despite this, ICANN does not consider it necessary to impose any further restriction or qualification on the use of .health domains, so whoever gets control of it would be free to allow its use by future registrants, no matter how irrelevant or misleading their content may be. This would evidently be subject to abuse if the awarded .health operator prioritizes profits over

health, which is likely to be the case. Indeed, it is expensive both to apply for and to maintain a gTLD (it costs \$185,000 nonreturnable up front and \$25,000 per annum); thus commercial pressure will bias domain controllers not to discriminate too much on who is allowed to use it—provided they are willing to pay enough.

ICANN posts information about the process of allocation in general and of the .health domain name in particular at <http://icannwiki.com/index.php/.health>. None of the three final candidates appeared to have the necessary experience or were prepared to seek a partner who has, to safeguard health information on the Net. The World Health Organization (WHO) originally bid for the right to operate a “.health” TLD in 2000; however, its application was not chosen in that proof-of-concept round. The WHO has since been discouraged—or, arguably, blocked—by a minority of influential member governments from making a bid for the domain name again. Senior officers within the WHO have been frustrated by restrictions even to voicing their objections to the three current proposals. They have now finally been able to write to the ICANN board⁵⁴ and have updated their website with proposed requirements for the management of health-related gTLDs, which ICANN appears to have summarily ignored.⁵⁵ There is a good case to be made that the allocation of this gTLD should have been postponed until questions about its use had been explored and safeguards against its abuse had been put in place.^{56,57} As Eysenbach notes in his JMIR editorial,

This perspective fails to acknowledge that quality assurance is not so much about censorship and “keeping information off” the Internet, but perhaps more about soliciting and providing additional information on prospective domain owners, for example conflicts of interest in the form of additional fields in WHOIS directories or standardized metadata.

No single body (let alone the domain registrar) should determine what is “correct” health information. It cannot be the goal to “censor” content or the messages on .health websites. It will always remain up to the website owners to ensure “message credibility,” and will always remain the responsibility of users to learn how to distinguish quality sites (“caveat lector”).

A gTLD can, if anything, only be a very indirect “quality label” for content, not least because when prospective applicants apply for the second level domain name, there is not necessarily any content to evaluate at that time, and withdrawing the address after content has been created would be a rather drastic and litigious measure unless there is blatantly illegal or harmful information. Thus, this debate should be less about content quality, rather, it should be about source quality.⁵⁸

Although the debate continues, ICANN has rejected several objections to the .health domain, even from its own independent objector. For example, ICANN’s At-Large Advisory Committee (ALAC), which “is responsible for considering and providing advice on the activities of ICANN, as they relate to the interests of individual Internet users (the ‘At-Large’ community),”⁵⁹ failed to persuade ICANN’s board that the International Medical Informatics Association (IMIA) represents a “clear delineated health community,” as required by ICANN’s “New gTLDs Guidebook.” Extraordinary as this may be, it appears to be typical of the way ICANN and its peripheral bodies operate. It is understood that, as a next

step, ALAC may request that the phrase “clearly delineated” be dropped from the guidebook requirement, in the hope that objections by international bodies, such as IMIA, may be viewed as legitimate expressions of community views.

Though some options remain for further intervention on the award of .health, all signs point to its eventual formal contracting to the winning applicant and the commercialization of the .health gTLD in the near future. What this could mean for the future of the health Internet and its health-related outcomes will inevitably be the subject of continued international debate and perhaps a precautionary case study of the evolution of ethics in health information.

Conflict of Interest/Acknowledgment/Disclaimer

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Notes

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