Invited Editorial

Samantha Adams Festschrift: Sam Adams and the Social Construction of Technology and Health—Implications for Biomedical Informatics

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Background

Clinical informatics, as an applied subdiscipline of biomedical informatics (BMI), must expertly use concepts from BMI core disciplines to design and deploy technologies to improve human health. The core disciplines include, among others, computer science, medicine, and social science. Applying social science concepts is perhaps the most challenging because issues related to people and organizations often have many interpretations, explanations, and solutions. Sam Adams, a social scientist who enjoyed engaging the most complex theoretical domains, made valuable contributions to thorny social problems at the intersection of technology and people. In this article, we argue that her work and the theoretical topics she chose for emphasis should be more widely consumed by practitioners in clinical informatics. As an example, we focus on social constructionism, one general theoretical topic she favored. Sam used social constructionism to explore domains relevant to today’s practicing clinical informaticist, including cybersecurity and social media.

Social Constructionism

“Social construction” and the related term “co-construction” refer both to a large body of scholarship and to a particular way of viewing knowledge systems and technologies.1 The basic premise is that systems of knowledge (for example, biomedicine, or more specifically genetics) and technologies of all sorts reflect the worldview of their designers and users. Further, it is argued that influential knowledge systems and technologies are the continually evolving products of a social process of design. For example, the International Classification of Diseases is a knowledge system that cannot be traced back to an individual designer; instead, it is the evolving product of negotiations and strategies of a variety of interest groups.2

Sociotechnical theory, as used in BMI, is social constructionist. Sociotechnical theory posits that social and technological systems continually shape each other, a process of co-construction. It is necessarily an interdisciplinary approach.3

Cybersecurity

Sam advocated for a sociotechnical agenda to address cybersecurity. Sociotechnical theory is interdisciplinary and employs multiple methods of analysis, both of which were among her strengths. She understood that different disciplines’ theories and methods offered important insights into complex problems such as cybersecurity. In 2015, she led a comparative review project of cybersecurity governance in five countries commissioned by the Dutch Ministry of Security and Justice.4 The report they produced focused on how cloud (and other) service providers can be accountable for how they manage personal, sensitive, and confidential information.5 It took an interdisciplinary approach to analyzing accountability and how to achieve it. It drew not only on standard methods for social and economic accountability assessment but also on the technology acceptance model developed in the information systems field by Davis,6 and on acceptance of technologies and the Diffusion of Innovations (DoI) Model, developed originally in Communications by Rogers.7 As they put it,

Understanding the interplay between these and other factors requires an interdisciplinary approach to understanding acceptance (e.g., value for money, market segmentation,
methods, all informed by the conviction that interdiscipli-
nary combination of theories, it was a novel combination of
and their policy recommendations. Not only was this a novel
questionnaires they administered, their security threat ana-
lysis, the accountability development tool they proposed,
and their policy recommendations. Not only was this a novel
combination of theories, it was a novel combination of
methods, all informed by the conviction that interdiscipli-
nary was needed to address the problem of cloud security
as a technological as well as people and organizational issue.
They commented on the relationship between an organiza-
three key concepts that shape social and economic account-
ability: trust, control and transparency. 5 These concepts
influenced the scenarios they developed, the interviews and
questionnaires they administered, their security threat ana-
lysis, the accountability development tool they proposed,
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nary was needed to address the problem of cloud security
as a technological as well as people and organizational issue.
They commented on the relationship between an organiza-
tion’s code of ethics and the degree of organizational and IT
architectural restructuring needed for demonstrable
accountability (p. 36).

Moreover, they saw it as both an ethical and legal issue as
well as a social, technological, and organizational one. Their
fictional scenarios “try to anticipate ethical, legal and social
dynamics, [which] are also an important part of a SEIA because
they help researchers anticipate the likely acceptance of a given
accountability tool, explore the dynamics of interaction
between current morality and new technologies, and outline
relevant governing mechanisms,” and the tool they developed
(p. 5) “educates the user on risks and threats to ensure the
ethical aspects of accountability (p. 22).”

This interdisciplinary thrust also is evident when consider-
ing security and privacy in health care. In Adams and Petersen,8
for example, the authors brought in the sociological criticism
of increasing medicalization of both society and cyberspace, as
well as the observation that the definition of “disease” is
shifting. Further, drawing on Foucault’s well-known analysis
of surveillance, she and colleagues brought together surveil-
lance studies scholars who are expanding Foucault’s ideas
together with eHealth scholars in a conference to inspire cross-
fertilizing these two previously unrelated streams of scholar-
ship.9 Their contributions included insights from legal, ethical,
social, and surveillance studies for cybersecurity in eHealth.
Sam recognized that as information technologies (ITs) have
infused health care and spread out into society at large through
mobile health applications, individuals and groups may feel
much more under observation in ways that lead to ethical,
legal, and social issues often lost in the excitement over what
these technologies can do. The resulting volume, therefore,
contains chapters on a range of these issues from scholars in a
variety of disciplines.

Sam’s chapter revisits Foucault and expands the discus-
sion beyond Discipline and Punish11 to consider The Birth of the
Clinic,12 his work on “the clinic” and “medical gaze.” Instead of
Foucault’s analysis of forms of knowledge and spatial config-
uration, or emphasis on how technologies increase surveil-
ance, she poses the theoretical question of how changing
structures and technologies change what the “clinic” is, and
proposes further research on the increasingly common status
of individual citizens as patients (i.e., “patientism”) by medical
professionals, and power relations between them.10

In doing so, Sam exhibits not only her command of
different disciplinary approaches and theories, but also her
bent toward co-construction, or the ways in which different
actors and perspectives interact to co-produce new struc-
tures, meanings, and behaviors. She plays disciplines off each
other to build new ideas, both theoretical and methodo-
dical. The interplay of methods, of theories, and of methods
together with theories, leads to knowledge creation, as in her
call for bringing together five separate arenas of study related
to cybersecurity, privacy, and the protection of (health) data:
(1) cybersecurity studies, which examine the sociopolitical
and technical governance of critical infrastructures and
mitigation of threats to systems such as botnets; (2) patient
safety, which examines concrete sociotechnical and organi-
zational challenges related to the protection of large-scale
health information technology (HIT) systems; (3) surveil-
lance studies; (4) studies in bioethics, which each examine
different aspects of (potential) threats to personal privacy
through networked technologies; and (5) legal studies,
which examine (proposed) changes to the laws and regula-
tions that govern data creation and exchange.4

Bringing these disciplines together to address cybersecurity
in health care would necessarily change how each addresses
cybersecurity, thereby co-constructing “cybersecurity” as well
as each discipline, which, in turn continues the cycle of
changing ideas of cybersecurity and how to achieve it. This
integrative thinking is evident in how she sees organizational,
ethical, and legal issues related to cybersecurity as a package
rather than as separate areas. It is not surprising that Sam was
active in the American Medical Informatics Association’s
(AMIA) Working Groups on Ethical, Legal, and Social Issues
(ELSI) and on People and Organizational Issues (POI). In her
perspective, ELSI and POI are interacting, interrelated issues,
each of which affect each other in a continuing interplay in
which all the issues are co-constructed by each other, the
technologies, the people, the organizations, the legal environ-
ment, and the like. As she points out: “digital technologies,
public policy, medical services and daily life continue to fold
into one another in various, sometimes unexpected, ways.”
Together they change ideas of health care delivery, what being
a patient means and involves, relationships between patients
and clinicians, health behaviors, ideas of privacy, what con-
stitutes illness, changes in power relationships related to
health care technologies and surveillance, and a host of other
important areas.10

Social Media
Public access to Web 2.0 applications and social media tools
such as weblogs, microblogs, wikis, media/file sharing sites,
and networking sites have digitized society and enabled a
democratization of knowledge by empowering citizens to
contribute to its production. Sam considered this shift to a
participatory society particularly important in health care,
which has historically been defined by a clear knowledge
hierarchy of expertise with classic forms of evidence (e.g., randomized controlled trials) considered the only valid knowledge to guide medical practices. Nonprofessionals (e.g., individuals with no form of medical training) are now able to contribute their own experiential evidence to provide an alternative account of reality to challenge the dominant knowledge hierarchy of existing medical evidence. Sam saw individual patients using social media to produce experiential information that can be co-constructed with other patient experiences to create a richer body of evidence for the collective benefit of other patients, health care professionals, policymakers, and commercial organizations. Sam’s case example of crowdsourcing to enable co-production of knowledge about pharmaceutical experiences describes how crowdsourcing applications shift the balance of power by acting as a “broker” to enable experiential knowledge drawn from individual experiences to complement existing sources of traditional pharmaceutical evidence.

However, many unanswered questions remain about how the co-construction of knowledge between multiple people and/or organizations works. Sam asks how Web 2.0 tools challenge, reinforce, and complement existing knowledge sources. Her work shows that social media tools act as a mediator between patients and other health system agents (e.g., people or institutions) by collecting information about individual experiences and repackaging this information to create experiential evidence about day-to-day health care practice. In understanding the co-construction process, Sam adopts the perspective of others in inferring that mediation from social media tools is not neutral but rather it transforms and translates information as part of the co-construction of knowledge. She extends existing work by focusing on the manner in which the mediation role influences the nature and structure of information exchange during the process of co-construction at both micro and macro levels. At a micro level, she explores the role of crowdsourcing for knowledge creation of patient experiences with pharmaceuticals and of eCoaches on individual behaviors. Sam states that it is still unknown exactly how patient experiences are used for co-construction of pharmaceutical knowledge, noting that at times patient experiences are edited or excluded during the processes of information mediation. She also contributes to the consumer health informatics field by showing that eCoaches can enable co-construction of behavioral changes to support healthy lifestyle changes, but she notes, too, that they can pose risks to individual users’ autonomy if people simply rely on the eCoach for reflection on behavior and selection of goals rather than co-constructing them. At a macro level, Sam explains that while social media platforms enable gathering, disseminating, and exchanging health-related information between hospitals and patients, there is still much to learn about how care institutions and broader health authorities use social media for patient engagement.

Conclusion

Sam makes an important distinction between co-construction in theory and how it is actually done in practice by showing that technology used to facilitate co-construction is not neutral but rather plays an active role in co-construction of knowledge. She affirms that co-construction is more than simply creating common knowledge but is in fact a complex interdisciplinary endeavor. Our examples of Sam’s work highlight a need to better understand the process of co-construction, and how people, processes, and technology interact during co-construction. Power or health literacy differentials can create divisions in health care consumers’ participation in the democratization of health-related knowledge. The contributions of researchers and health IT designers will be enriched if they are informed by an analysis of the power asymmetries that are being perpetuated by computational tools. Sam’s work complements others in emphasizing the need to draw upon social science disciplines to better understand how co-construction occurs and evolves over time. Incorporating participatory approaches and social science methods in the design and evaluation of BMI tools and applications, as Sam did for cybersecurity and for social media, would help us understand how informatics tools are socially constructed, how that affects their use and effectiveness, and how we can make this process more deliberate.

One of Sam’s important contributions was the linkage of people and organizational issues with ethical and legal issues. This may seem an obvious connection, but we too often pay little attention to how individual, organizational, and societal responses to technological issues produce many of our ethical dilemmas, and how the interplay of the social and technological present different views of ethical and legal issues. Studying how ethical dilemmas are produced by people and organizations, and then reckoned with by people and organizations, will produce key insights for informatics in the coming decade, preparing the discipline for participation in important societal conversations. Sam’s dedication to advancing society’s thinking related to ethical, legal, and social issues was evidenced in her active involvement in the related AMIA Working Groups. She participated in the analysis and writing for a 2015 paper that examined thousands of comments on an influential AMIA listserv. Over several years, she served as both chair and co-chair of the Diana Forsythe Award Committee. She facilitated as the group reckoned with the expanding scope of the Award’s domain: the intersection of social sciences and technology. Sam represented innovative areas of research, particularly the area of digital ethnography, and its inclusion in the Award’s domain is the result of her advocacy.

In this article, we illustrate how Sam’s attention to theoretical issues produced insights directly applicable to clinical informatics. They led to better understanding of how people use social networking in health care and how cybersecurity can be improved. Sam’s penchant for learning from and contributing to other disciplines is evident in her work. As her cybersecurity analysis shows, it enabled recommendations for improving HITs, their use, and policies governing them. We encourage working informaticists to become familiar with the language and concepts that underlie science and technology studies and related theories. This integrative approach and knowledge of multiple theoretical and  

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disciplinary approaches can improve one’s awareness of the social implications of design features and choices, resulting in more enlightened informatics tools and research.

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References