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## **Social Informatics and Consumer Health**

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## Social Informatics and Consumer Health

The dominant contemporary conceptualization of consumers is as individual seekers of health information for their personal use. This individualistic view informs the development and deployment of technically-sophisticated systems is flawed in two ways. First, individualistic views overlook the socially-embedded nature of consumer health engagements. Second, such a view reifies the rather problematic expert-centric view of health care. In this chapter I focus on how social informatics helps to both illuminate these issues and redress them through alternative conceptualizations.

Working groups focused on Consumer Health Informatics with the American Medical Informatics Association and the International Medical Informatics Association advocate for a range of needs relative to consumer's health information needs (AMIA, 2003; IMIA, 2003). However, they focus on helping individual's make decisions about personal health issues (e.g., NIST, 2003). Conversely, the Pew Internet and American Life Project's reports note that women and well-educated people are seeking health resources information, primarily to help inform others (Pew, 2003). Further, the Pew's empirical findings make clear that people use the Internet as a forum for emotional support and for practical, daily help in coping. Finally, the findings of the Pew researchers are that these searches are done via search engines, with little fact checking, and convenience and anonymity are valued above breadth and validity<sup>1</sup>.

This contrasting view on consumer health behavior is problematic. Evidence supporting a view of consumers as embedded in a web of social relations, set in physical and temporal contexts, and often seeking information on behalf of others is difficult to reconcile to the current discourse on consumer health-information seeking behavior. To help address this gap, in this chapter I introduce you to the concepts and findings of social informatics. I do so to help reframe your understanding of, and issues with, consumer's information seeking regarding health and medical information and their use of information technologies and information systems to support this information-seeking behavior. In this chapter I:

1. Define and explain the concepts and findings of social informatics.
2. Examine consumer health opportunities and unexplored issues from a social informatics perspective.

Thus, this chapter serves as an introduction to social informatics, and in doing so provides a lens for consumer health informatics scholars, systems developers and policy-makers to reflect on the current approaches to engaging issues in (and with) consumer health<sup>2</sup>. My premise is simple: social informatics can assist consumer health informatics scholars, systems builders, and policy makers in developing more robust and useful theories, applications, and policies.

Social informatics is the body of rigorous empirical research that focuses on the relationships among information and communications technologies (ICT) and the larger social context in which these ICT exist. By using ICT I include formal information systems such as medical records systems through to the informal and often highly-personalized collection of devices such as phones, cellular phones, personal digital assistants, etc., that people use to find and share information. Thus, ICT is a plural, fluid, and poorly defined placeholder that I use to evoke the concept of a web of computing (Kling and Scacchi, 1982). Focusing on context highlights that ICT exist within a larger social milieu through which the uses of that ICT can be understood. In saying this I explicitly connect social with technical: in the rest of this chapter I refer to this intimate interdependency as a socio-technical relationship.

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<sup>1</sup> The Pew findings reflect more the missions of the American Medical Informatics Association: People and Organizational Issues working group (see <http://www.amia.org/working/poi/main.html>) and the International Medical Informatics Association's Organizational and Social Issues working group (see [http://www.imia.org/search.lasso?-database=organizations.fp5&-response=WG\\_profile.html&-layout=CGI&-sortField=workgroup\\_SIG&-sortOrder=ascending&-op=bw&type=WGSIG&-maxRecords=1&-skipRecords=13&-search](http://www.imia.org/search.lasso?-database=organizations.fp5&-response=WG_profile.html&-layout=CGI&-sortField=workgroup_SIG&-sortOrder=ascending&-op=bw&type=WGSIG&-maxRecords=1&-skipRecords=13&-search)). These group's web sites note that there is a long tradition of research into, and a cumulative body of evidence on, the larger social and organizational dynamics surrounding individuals who seek health information and interact with health-information-providing systems.

<sup>2</sup> As I will discuss, social informatics is not a theory, a method, or a domain. Social informatics research spans disciplines and research domains. My particular interest in the relationships between uses ICT and organizational effects shapes the literatures I cite and examples I present.

Social informatics research shares a common perspective and often common findings, as I and others have noted. Social informatics work, however, is found in a range of disciplinary literatures. In this way, social informatics is trans-disciplinary. Acknowledging this helps to give voice to common findings found in dispersed bodies of related research literatures. For example, I summarize three studies, each from relevant literatures, focused on different social settings and using different ICT to showcase the commonalities of social informatics research.

Kaplan (2003) reports on a study of patients interacting with a telemedicine system (the trial being done in the New England region of the United States (US)). The system was designed to provide an automated and interactive response to patients dealing with changes in their physical activity and eating (in response to medical procedures). The interactive system was driven by an expert-system that had both diagnostic and response questions about health and physical activity. Kaplan found that this clinical system was much more than a fact-dispensing interaction with its clientele. Participants reported developing an attachment to the automated voice, looking forward to the social interactions with the system, and even developing personal feelings towards the voice, often asking questions far beyond the range of responses anticipated by the designed (leading to odd interpretations of what was reported by the automated clinician). Many of the participants were lonely and isolated, and this clinical system served as much more than the clinical expert its designers anticipated. The automated system became a friend and confidant – more valued because it “listened” than for its medical advice.

Patterson, et. al (2001) reports on a study of automated (bar coding) systems used by nurses in a US veteran’s hospital. The system, hosted on a personal digital assistant, was used to help automate the work flow of nurse, better monitor patient interactions and medications, and reduce errors in the human’s practice of medicine. Patterson and her colleagues found that the design of the system and its hosting device did not fit the nurse’s work. The device masked details of the medical record and the limited interface made it difficult to search, read and record information. The pre-designed workflow system did not accommodate moves (such as demanding medicine to be administered to patients when the patient was in another part of the hospital for test. This would be recorded as a nurses’ error). This led to nurses using work-around and often increasing the number of possible mistakes (not reducing them). Simply the information system did not account for the complex coordination needs, importance of worker-to-worker social interactions, and the structural demands of the organizational settings.

Etzioni and Etzioni (1999) focus on computer-mediated-communication (CMC) and report that the creation of sustainable (stable) communities of participants (stakeholders) is critical to CMC-system. They explore the role of community and extend observations of behavior in face-to-face communities to what they mean in a computer-mediated world. Their analysis maps aspects of community with features of ICT that support computer-supported communities. In doing this they raise both ICT design and ICT use issues, reflect on the ways that the social context formed by these communities shapes CMC use, and suggest several hybridized CMC designs that would better meet the needs of virtual communities.

The Kaplan, Patterson, et al, and Etzioni and Etzioni papers focus on different types of problems, look at different types of ICTs, draw on different literatures, use different theories, and are set in different contexts. However, these studies highlight similar conceptual issues and their findings have much in common. For example these studies suggest that ICT uses leads to multiple and sometimes paradoxical effects. All three studies describe how ICT use shapes thought and action in ways that benefit some groups more than others and these differential effects. Third, all three studies depict a reciprocal relationship between ICT and their context. We return to these points, below.

## **1. What is Social Informatics?**

Six elements help to both define and bound what is meant by social informatics.

### *1.1 The Problem-Oriented Nature of Social Informatics*

Social informatics is problem oriented. Just as the human-computer interaction (HCI) literature reflects the problematic relationships between individuals and computers, and the computer-supported cooperative work (CSCW) literature reflects the problematic relationships between groups of people and computers, the social

informatics literature reflects the problems that arise from the bi-directional relationships among social context and ICT design, implementation, and use. Social informatics research spans levels of analysis, often by making explicit links between particular levels of social analysis and the larger social milieu in which computing takes place. In this way, social informatics is similar to other areas of study that are defined by a problem such as gerontology, software engineering, urban studies, etc.

Social informatics research is further characterized by its inclusion of normative, analytical, and critical orientations. The *normative orientation* refers to research whose aim is to recommend alternatives for professionals who design, implement, use or make policy about ICTs. This type of research has an explicit goal of influencing practice by providing empirical evidence illustrating the varied outcomes that occur as people work with ICTs in a wide range of organizational and social contexts. For example, much of the participatory design research focuses on identifying the nuanced ways in which users come to understand and adapt how they work with information systems.

The *analytical orientation* refers to studies that develop theories about ICTs in institutional and cultural contexts or to empirical studies that are organized to contribute to such theorizing. This type of research seeks to contribute to a deeper understanding of how the evolution of ICT use in a particular setting can be generalized to other ICTs and other settings. One example is Kling's (1980) depiction of various perspectives on ICT use in organizations.

The *critical orientation* refers to examining ICTs from perspectives that do not automatically and "uncritically" adopt the goals and beliefs of the groups that commission, design, or implement specific ICTs. The critical orientation is possibly the most novel (Agre & Schuler, 1997). It encourages information professionals and researchers to examine ICTs from multiple perspectives, such as those of the various people who use them, as well as people who design, implement or maintain them. The critical orientation also advocates examination of possible "failure modes" and service losses. Critical approaches provide great insight into how ICT can be better designed (e.g., Kaplan, 2003, Patterson, et. al., 2001)

### *1.2 Empirical and Theory-Based Focus of Social Informatics*

Social informatics work is empirical. The intent is to help make sense of the vexing issues people face when they work and live with computing. This work is always set in the context of social milieus such as work groups, communities, cultural units, societies and/or organizations.

Social informatics research is often characterized by its use of the wide range of social theories that explicitly engage context in a holistic manner. By social theory we invoke the wide range of perspectives that seek to represent, define, and predict how humans enact and maintain social order, social structures, and social interaction (e.g., Sica, 1998, p. 10; Ritzer, 1996)<sup>3</sup>.

### *1.3 A Socio-technical Perspective*

Social informaticians conceptualize context as comprising interdependent and multi-level networks of socio-technical links (e.g., Castells, 1991; MacKenzie & Wajcman, 1999). Strum and Latour (1987) emphasize that these links are not merely social, since humans use technologies such as ICT to construct or enforce their view of reality through symbolic and material bonds. Often the literature uses different terms to describe this socio-technical arrangement. No matter the term(s) used, social informatics research is premised on the belief that even common technical components cannot be understood apart from the social and organizational milieu in which they exist. Simply, computing cannot be considered in isolation but must always be studied in specific contexts.

A socio-technical perspective makes clear that people are social actors. That is, people's individual autonomy, their agency, and their behaviors, are shaped by the social norms, organizational forces, and (the social and physical)

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<sup>3</sup> The forms and meanings of social theory are, themselves, a field of vigorous inquiry and there is not space in this chapter to engage in a detailed discussion of what is social theory. For those interested in exploring some of the most widely used social theories, see Ritzer (1996). For those interested in discussions of the roles, meanings and roots of social theory, see Sica (1998).

structures that surround them (Lamb and Kling, 2003). These structures can be as straightforward as office layout. But, structures also include the uses of computer systems, the inherent organizational structure of data, procedures and interactions, and authority structures based on power and knowledge. Viewing people as social actors makes clear that they are often acting in very constrained, if not sometimes prescribed, ways.

A socio-technical perspective also emphasizes the ensemble view of computing (Orlikowski and Iacono, 2001). In this view the elements of computing are seen as enmeshed into the institutional structures of particular situations and the social-actor nature of individuals. Such an institutional appreciation for ICT makes it difficult to abstract “best practices” or de-contextualized findings drawn from one site and apply or extrapolate them to a second site.

### *1.5 Trans-disciplinary*

Social informatics research is being done in many disciplines including information science, communications, sociology, anthropology, information systems, management science, education, and library science, to name some. Often scholars whose work focuses on one domain (such as hospital emergency rooms) do so without knowing that similar work, often leading to similar findings, is being done in another domain (such as software development groups). In this way social informatics is a “trans-discipline:” its literature both spans and links research from disparate fields. Further, while the term “social informatics” may be new, social informatics research is not. Researchers from these various fields have been studying the social and organizational aspects of ICTs for more than 25 years (Kling, 1980). This work falls under a range of conceptual labels including (but not limited to) the “social analysis of computing or technology,” the “social impacts of computing or technology,” “information policy,” “computers/technology and society,” and, more recently, “computer-mediated communication” (Kling, 1999, p. 1). The sheer number of related fields and the use of a range of terms means that the research findings and insights have been difficult for scholars and teachers to access (Kling, 2000; Kling, Rosenbaum, & Sawyer, forthcoming, p. 12). Moreover, given this dispersion, it is (oddly) possible for a scholar to contribute to the social informatics literature without ever having considered their work to be a part of this (or any larger) corpus of similar findings.

### *1.6 A Form of Informatics*

The meaning of social informatics rests in part on the broad, evolving and debated definition of informatics. By informatics we mean the study of information content, representation, technology, and the methods and strategies of its use (see Brookes, 1980). Informatics is a term commonly used outside of North America to refer to a range of computing research<sup>4</sup>. While there is an ever-growing number of informatics research areas (e.g., medical informatics, legal informatics, archive and museum informatics, consumer health informatics, bio-informatics, etc).

A specific form of social informatics is that work focused on formalized organizational or group boundaries, which we call organizational informatics<sup>5</sup>. Social informatics arose as a descriptor through a series of discussions among like-interested researchers in the early 1990s. Often these conversations were led by or included the late Rob Kling, who maintained one of the most comprehensive social informatics web sites (see footnote #4) and whose work has been an instrumental part of coalescing social informatics into the inter-discipline I write of in this chapter.

In summary, what then, is social informatics? According to Kling (1999, p. 1): “A serviceable working conception of ‘social informatics’ is that it identifies a body of research that examines the social aspects of computerization. A more formal definition is the interdisciplinary study of the design, uses and consequences of information technologies that takes into account their interaction with institutional and cultural contexts.”

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<sup>4</sup> See [www.slis.indiana.edu/SI](http://www.slis.indiana.edu/SI) for more discussion of informatics. This site, maintained by the late Rob Kling, contains a brief history on the emergence of the term and some key contributors. A link to a 1997, NSF-sponsored, workshop on social informatics points to a partial list of additional contributors who attended, commented on, or whose work directly shaped the workshop report. This workshop report can also be found at the Social Informatics website.

<sup>5</sup> We consider organizational informatics a subset of social informatics. For convenience, in the rest of this paper we use social informatics to denote *both* social and organizational informatics.

### 1.7 What Social Informatics Is Not

Many academic approaches besides social informatics provide theoretical insight and/or commentary on the relationships among ICT's uses and the human condition. In this section we highlight some of these approaches and explain how they differ from our conceptualization of the inclusive literature represented by us as social informatics.

*A theory.* Like HCI and CSCW, social informatics is best seen as a large and growing federation of scholars focused on common problems. There is no single theory of social informatics and there is no claim being made that the research in this field is pursuing one particular theoretical notion. Currently there are many theories being used by social informaticians and we return to this point in section two. In section four we point to some contemporary work oriented towards theory building. But, even from the most liberal perspective, social informatics is not a theory.

*A method.* Social informatics research is characterized by pluralistic approaches to the conduct of inquiry. It is pluralistic in that it is not method-specific. Social informatics researchers employ a variety of methods, ranging from the observational studies (Suchman, 1996), secondary data analysis (Kling, 1980), surveys (Attewell & Battle, 1999) and multiple methods (Crowston, Sawyer & Wigand, 2001). In this way the social informatics literature differs from fields such as operations research or linguistic analysis that are primarily defined by their methods.

*Direct effects (or tool) approach.* Direct effects models underlay the earliest and often most simplistic efforts to anticipate the social consequences of computerization in organizations (see, for example, Negroponte, 1997). Tool views provide little to social informatics given the relatively simple views of how people interact with the ICTs.

*Punditry and futurizing.* In addition, social informatics differs from other non-academic commentary about ICTs and society. One of the more common forms is the punditry of futurizing: glossy conceptualizations of the future impacts of ICT on society with little (or anecdotal) support (e.g., Toffler, 1991). This, and other forms of futurizing, may often be both thought-provoking and popular. But, these prophesies are rarely validated by empirical study and are often simplistic or misleading. In this way the public commentary on the value of website such as WebMD reflect punditry.

## 2. Social Informatics Foundations

Three common findings arise from the empirical and rigorous research base of social informatics.

### 2.1 The Roles of the Social Context

The mutual interdependence between ICT and social context frames social informatics research contexts (Kling, 1980; Argyres, 1999; Abbott, 1995). By social context we mean a holistic perspective among levels of social analysis, particular characteristics that help to define a level of analysis, characteristics that act as forces on the various levels of analysis, and characteristics which provide the backdrop and perspective from which an understanding of the problem of interest can be made. The exact nature of the social context is intimately related to the problem of interest. This suggests that the characterization of, and factors of interest within, context will vary and the researcher must set out the levels of analysis and factors through either *a priori* depiction or *post hoc* description. But, all social informatics research will represent social context.

Research that reduces the larger social context to one or two variables, such as level of uncertainty in the environment or some other surrogate, is not typically considered as social informatics. However, factor-based studies that provide a richer picture of context can contribute to social informatics.

As we stated earlier, social informatics researchers explicitly acknowledge that ICTs are conceived, developed, configured and/or used within a nuanced and interdependent socio-technical system (Lamb & Kling, 2003). Thus, ICT are in a relationship of mutual shaping with context (Orlikowski & Baroudi, 1991; Bijker, 1995). For example, the embedded nature of ICTs influences the ways people develop them, the kinds of workable configurations they propose, and how they implement and use ICTs.

## 2.2 Common Social Informatics Findings

Three common findings come from the empirical work in social informatics:

1. ICT uses lead to multiple and sometimes paradoxical effects.
2. ICT uses shape thought and action in ways that benefit some groups more than others and these differential effects often have moral and ethical consequences.
3. Reciprocal relationships exist among ICT design, implementation, use and the context in which these occur.

### 2.2.1 ICT uses lead to multiple and sometimes paradoxical effects

Social informatics studies highlight the complex outcomes of ICT use in two ways. First they show that a particular ICT's impacts are rarely isolated to a desired area, but rather spread to a much larger number of people through the socio-technical links that comprise context. Second, these studies typically highlight unforeseen and unintended outcomes, which, in many cases, may be contrary to the original intentions for the ICT. In summary, these examples serve to illustrate the first common finding of social informatics research: ICT uses have both far-reaching and unexpected outcomes. This implies that we should not assume that it is possible to fully understand the impacts of a particular ICT use. It is likely that any given ICT will shape elements not immediately adjacent to it through connections of socio-technical links. Further, we cannot always expect that ICTs will have the (positive *or* negative) effect we expect them to have.

### 2.2.2 ICT uses shape thought and action in ways that benefit some groups more than others and these differential effects often have moral and ethical consequences.

The basis of our second common finding is that ICT uses act as socio-cognitive structures that shape thought and action. Following Ritzer (1996) we understand structure to include both large-scale social structures that shape interaction and micro-structures involved in individual human interaction. The social informatics approach recognizes that these structures shape thought and action in ways that benefit some groups over others and that this structural favoritism often leads to moral and/or ethical consequences.

### 2.2.3 Reciprocal relationships among ICT design, implementation, use and context

The third common finding that arises from contemporary social informatics literature is that there is a reciprocal (bi-directional) shaping between ICT and its socio-technical context. That is, social informatics research often leads to discussion of how context shapes ICT or ICT uses and how these ICTs and ICT uses shape their context.

## 2.3 Context and Levels of Analysis in the Social Informatics Literature

We noted earlier in this chapter that social informatics scholars conceptualize context as socio-technical networks of influences. They recognize that these network exist at what Klein, Dansereau and Hall (1994) call different levels of theory or the "target level at which the researcher aims to depict and explain. (p. 198)" In social informatics work this typically includes formal and informal work groups; departments; formal organizations; formal and informal social units like communities or professional occupation/associations; groups of organizations and/or industries; nations, cultural groups and even whole "societies" (MacKenzie & Wajcman, 1999; Castells, 1991). Thus, one way of understanding context is to focus on the level of theory and analysis that social informatics scholars portray in their research.

## 3. A Social Informatics Perspective on Consumer Health Informatics Research

In this final section we use the principals of social informatics to help reframe some of the ongoing issues and opportunities in consumer health informatics. There seems to be no shortage of issues and opportunities in this area, and here we draw on Eysenbach, 2002 who notes that the emerging orientation towards evidence-based medicine, increased use of information and communication technologies to get information and deliver services regarding health, and the growing awareness of the need to equalize relationships among health professionals and lay people

are tied to cutting healthcare costs. Eysenbach (2002) notes four areas of interest to consumer health informaticians:

1. Bringing medical knowledge to consumers.
2. Making electronic health records accessible to patients.
3. Building decision aides to support consumer's choices.
4. Developing quality control mechanisms for health information available over the internet.

### **3.1 Bringing medical knowledge to consumers**

As we noted at the chapter's start this is typically conceived as targeting the brain and behavior of an individual. A social informatics perspective suggests that these people are embedded in institutional settings such as families, workplaces and neighborhoods, with each of these institutional contexts both steering and enabling actions (Kulthua, 1991). This social-actor perspective further suggests that this knowledge passing must be tied to a larger discourse (as public health professionals have known for years), must be multi-channel, and rarely is connected to formal medical systems or sources of knowledge. This also suggests that application design must embrace the language and idioms being used, requires multiple channels (such as the telephone, internet links and perhaps even the television) and needs to be built to enable dialog (a consumer-centric view of interactions, not question answering (a physician-centric view of interactions) (Berg, 2002).

### **3.2 Making electronic health records accessible to patients.**

Two issues are often discussed relative to health records. First, to make people's medical records more transparent. This, again, is tied to the consumer as an individual. Second, and tied to access, to raise consumer's level of understanding about health-related issues. A social informatics perspective suggests re-conceptualizing medical records as also a family or community property (Borgman, 2000). This acknowledges that people are often looking on behalf of others, are sharing within family and other social units, and making collective sense of medical information. Further, a social informatics perspective highlights that there are different contexts of use: those who engage in their medical information in response to emergencies act much differently than do those engaged in long-term care and management of some particular illness. Application designers should focus on balancing private and public access (like a library) rather than as a personal characteristic.

### **3.3 Building decision aides to support consumer's choices.**

By framing decisions as a particular person's personal choice seems central to current thinking in consumer health informatics. It also stands in stark relief relative to relevant contemporary data about how people interact with health information and make decisions (Pew, 2003). Decision-aids are an outgrowth of medical systems and are likely to be as obtuse and off-putting as have been people's interactions with most health professionals (e.g., Kaplan, 2003). A social informatics perspective suggests that this approach is not viable.

### **3.4 Developing quality control mechanisms for health information available over the internet.**

Nothing in the literatures on internet usage or human information seeking suggests this is possible (Bishop, Mehtra, Bazell and Smith, 2002). By developing access to information as a quality control issue frames internet access to medical information as a large-scale problem of people making poor or uninformed choices. This framing neglects the powerful forces of family, friends and neighbors in both traditional and internet-driven consumer-health informatics. This was a 'problem' with the conceptualization of patient/professional relationships that pre-dates the internet and quality control efforts are unlikely to remediate a long-standing problem. A social informatics perspective suggests that focusing efforts to develop, facilitate and enable localized discussions and sharing (Hampton, 2002, Hansen, 1999).

### **3.5 Two further suggestions for consumer health informaticians**

An emerging trend in the social informatics literature is the development of theories and models that draw upon, and/or extend, social theory to more fully account for the effects of ICT. Consumer health informaticians have the opportunity to contribute to this broad goal while also pursuing more socially-relevant and encompassing theories of

consumer's health information behaviors.

Second, the expertise with clinical trials provides health informaticians a methodological means to observe the evolution, and contribute to shaping the design of information systems over time. Imagine a trial of two systems: one based on the knowledgeable individual premise that underlies current medical information systems and the other premised on social actor perspectives of users. In the former, its content and advice focused. In the latter, the design is focused on sharing and responding. The efficacy of these systems can be compared. And, their subsequent development and operations can be evaluated and assessed over time. Simply, the difference among current views on consumer health informatics and a social informatics perspective of the same issues is both a conceptual and empirical question, and these are the type where our science can help.

In summary, the context-dependency, methodological pluralism, problem-orientation and trans-disciplinary character of social informatics research can help contemporary consumer health informaticians. A social informatics perspective leads to advocating for broad-scale, contextually-based research programs where people are characterized as social actors and the roles of ICT are set within institutionally sensitive contexts. Further, a social informatics perspective focuses our awareness of ICT's varied influences and to provide us a means of engaging in larger-scale discussions of these influences. In this way, social informatics research provides a means of educating practitioners, and of extending the research scope of researchers.

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