Consumer Health Informatics: Empowering Healthy-Lifestyle-Seekers Through mHealth

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Abstract

People are at risk from noncommunicable diseases (NCD) and poor health habits, with interventions like medications and surgery carrying further risk of adverse effects. This paper addresses ways people are increasingly moving to healthy living medicine (HLM) to mitigate such health threats. HLM-seekers increasingly leverage mobile technologies that enable control of personal health information, collaboration with clinicians/other agents to establish healthy living practices. For example, outcomes from consumer health informatics research includes empowering users to take charge of their health through active participation in decision-making about healthcare delivery. Because the success of health technology depends on its alignment/integration with a person's sociotechnical system, we introduce SEIPS 2.0 as a useful conceptual model and analytic tool. SEIPS 2.0 approaches human work (i.e., life's effortful activities) within the complexity of the design and implementation of mHealth technologies and their potential to emerge as consumer-facing NLM products that support NCDs like diabetes.

Keywords

mHealth, sociotechnical, human factors, diabetes, consumer health informatics

Acronyms

American Medical Informatics Association	AMIA
Biomedical informatics	BI
Consumer health informatics	CHI
Electronic health	eHealth
Electronic medical records	EMR
Health informatics	HI
Health information technology	HIT
Healthy living medicine	HLM
Mobile health	mHealth
Noncommunicable diseases	NCD
World Health Organization	WHO

How many times has it been said that "healthcare is a risky business?" Patients are at risk from noncommunicable diseases (NCD) and poor health habits,[1] with interventions like medications and surgery carrying the risk of adverse effects. The Institute of Medicine's report *To Err is Human: Building a Safer Health System*[2] highlighted the risk of adverse medical events in clinical settings, with patient deaths in United States (US) hospitals annually exceeding 44,000, at a cost of $38 billion. This paper will address ways that consumers are increasingly moving to healthy living medicine (HLM) to mitigate such health adversities.[3] The goal of HLM is not only to reduce the effects of NCD,[4] such as diabetes and heart attack, but to increase patient engagement and improve patient-health system interactions so that, ultimately, people establish and sustain healthy living practices.[5,6,7] Through decades of research in the field of consumer health informatics (CHI) and the exponential growth of mobile technology in the last decade, healthy living seekers increasingly have the means to control personal health information and engage with their health over time and space.[8] In particular, people from all walks-of-life now have access to a range of electronic health (eHealth) tools to support health and mitigate disease progression.

Consumer Health Informatics—A Subdomain of Biomedical Informatics

To improve human health and advance the mission of healthcare in the US, biomedical informatics (BI) has evolved as an "interdisciplinary field that studies and pursues the effective uses of biomedical data, information, and knowledge for scientific inquiry, problem solving, and decision making, driven by efforts to improve human health."[9] Particularly, BMI is the management, study, and use of medical information,[10] including the "cognitive, information processing, and communication tasks of medical practice," with information science and technology to support such tasks.[11 12] Kulikowski and colleagues note that the phrase "biomedical and health informatics" is also used to describe the full range of application and research that underlies its scientific discipline. They continue—that BI is the core scientific discipline that supports applied research and practice, including health informatics (HI). Hence, HI problems are solved by BI subspecialties who do applied research in the context of clinical and public health systems and organizations, often defined as clinical informatics and public health informatics.[13]

Another subdiscipline of HI is consumer health informatics (CHI), which is the study of consumer information needs and healthcare technologies, as well as the implementation of methods of making information accessible to consumers.[14] As perhaps one of the most challenging and rapidly expanding field in HI; it is paving the way for health care in the information age by integrating consumers' preferences into medical information system.[15] CHI draws upon the social and behavioral sciences to inform the design (e.g., mobile application interfaces) and evaluation of such technologies.[16] CHI research supports problem solving that impacts quality healthcare and the promotion of healthy behaviors, peer information exchange, and social support.[17] Particularly, CHI research is helping people with NCDs navigate the complex healthcare ecosystem with both real-time monitoring, mobile technologies, as well as easy access to evidenced-based guidelines that support disease management.[18]

Figure one illustrates the framework of BI, HI, and its multiple subdomains, of which CHI is subordinated. Although considerable overlap exists between CHI and eHealth, differences are apparent. For example, eHealth is a convergence of CHI products and services that include the

Internet and mobile technology innovation from the perspective of health data analytics. That is to say, while CHI is a research discipline given to the study of problems related to electronic health information delivery to patients, eHealth refers more specifically to those electronic tools and services available over the Internet, including wireless media such as Web-compatible mobile phones (e.g., mobile health) and personal digital assistants (PDAs).[19] On one hand, CHI is an academic discipline devoted to the exploration of new possibilities that the Internet provides for public health and health education, while eHealth is concerned with designing solutions that facilitate people in accessing information in their personal electronic health record, such as diagnosis, lab work, and prescribed medications, etc.[20]

In one study, researchers did a systematic review of CHI literature from 1999 to 2013 regarding the impact of eHealth technologies on healthcare delivery. Their findings suggest that new CHI applications are being used on a variety of platforms, e.g., the Web, texting apps, and mobile phones, to assist patients with self-management. CHI applications included “reminders and prompts, delivery of real-time data on a patient’s health condition to patients and providers, web-based communication and personal electronic health information.” Their findings also suggest that such tools enhance healthcare decision making and are a means for clinicians, patients, and others to exchange health information for personal and public use. A key CHI trend noted was the integration of services, technologies, media, data, knowledge and communities, with increased collaboration among healthcare organizations, governments, and the IT industry in the innovation of new eHealth tools—tailored to the needs of the healthcare consumer.[21]

FIGURE ONE PIC PLACED HERE.

Fig - Subcategories of the biomedical and health informatics field, with areas of application and practice, spanning from basic research to applied research. Adapted from Shortliffe and Blois (2006),[22] Kulkowski et al (2012), and Hersh (2009).[23]

mHealth—Empowering People and Communities to Collaborate

Ongoing research in CHI is showing promising results with eHealth technologies that provide the means to upload data to one's electronic health record (EHR) from wearable and mobile health (mHealth) devices and apps that facilitate health objectives.[24] This aligns with AMIA's vision for advancing EHR use and usability by facilitating "Digital and Mobile Patient Engagement" through "interoperability between patient's mobile technology and the EHR."[25] In a healthcare CHI shift to a patient and home-centered paradigm, self-care management will bring about extended responsibilities for patients, families, and communities.

As a proliferating sector of eHealth, mHealth is emerging. mHealth is mobile computing, including wireless, medical sensor and communication technologies (e.g., smartphones and tablets) used for health information delivery and promotion, chronic disease management and wellness planning. mHealth supports mobile health-related activities using both text messaging platforms, apps, sensors that track vital signs and health activities, cloud-based computing for collecting and analyzing health data—more broadly, any mobile technology used to facilitate ubiquitous communication and interaction with data, information, or services—with the goal of improving personal health and health behaviors.[26]

As of 2013, researchers stated that approximately 75 million individuals (31% of the US population) use mobile phones for health information and apps, with the average age being 35, (54% being male).[27] A 2014 report from the Research2Guidance Research Group suggests that the number of mHealth apps has more than doubled in 2.5 years to reach more than 100,000 mobile apps, of which 31% are used by the chronically ill and 28% by people with interests in health and fitness. Research also demonstrated that 82% of all mHealth apps generated less than 50,000 downloads in 2013, whereas the top 5% reached more than 500,000 downloads. More importantly, mHealth apps provide a considerable impact on healthcare system costs, reducing non-compliance and hospital readmission costs up to as much as 55%. Of no surprise, the mHealth sensor market is witnessing rapid growth with projections that it will grow to over $26 billion by 2017.[28]

The market for mHealth is expected to surpass $200 billion by 2020.[29] One example of this booming market can be seen with the MyFitnessPal app (launched in 2005), which helps consumers in their quest for health and fitness to track calorie intake, make healthy food choices, and glean and discover insights through advanced analytics by combining population data with personal data. The app, which interfaces with wearable monitoring trackers (e.g., Fitbit and Jawbone), grew to over 40 million users worldwide by late 2013.[30] mHealth has proven to be one of the most powerful agents in offering people accessibility, convenience, control and management of personal data.[31,32] The outcomes of such advancements have enhanced communications and transparency of information, including “greater interaction between providers and their patients” based on new patient health management models that will routinely include “app-generated data into the treatment record and subsequent care plan.” [33]

As noted, the mHealth market is rapidly evolving, with the potential to make a dramatic impact on HLM. As such, there is still more research needed to investigate the impact of these technologies on real health outcomes. Two recent comprehensive studies (done in 2013 and 2016) reviewed the field of mHealth research to date. The first study focused on the impact of mobile phones on health. Of 117 articles reviewed (published: 2002—2012 in 77 journals), they had five common factors: (1) A clear focus on chronic conditions, (2) The participant sample increased over time when testing mobile health applications, (3) A majority of the studies tested basic mobile phone features (e.g., text messaging), while only a few assessed the impact of smartphone apps, (4) A shift from assessment of the technology to its impact and increase, and (5) The outcome measures used in the studies were mostly clinical, including both self-reported and objective measures. In summary, the research findings suggest that research interest in mHealth is mounting with an increase in complexity of research design, as well as a diversity of influences on the healthcare market.[34]

The second study focused on current practices and recommendations for designing, implementing, and evaluating mHealth technologies that support the management of chronic conditions among older adults. The researchers identified 42 articles that met the inclusion criteria. Most papers outlining mHealth solutions discussed the products designed for use by patients and or healthcare providers. In sum, the study suggests a limited yet increasing use of mHealth in home healthcare for older adults, with recommendations for mHealth products that are more user-centered and collaborative to better enhance feasibility, acceptability, and usability,[35] based on methodologies found in the fields of human factors engineering and human computer interaction.

The notion of health empowerment continues to be promoted and applied throughout several fields of health services,[36] e.g., public health,[37] global health,[38] health promotion,[39] and consumer health informatics.[40,41] For example, AMIA recognizes that CHI is about consumer engagement through the use of mHealth applications, where the growing emergence of patient control of data includes increasing access.[42] Since the late 1970s, the term “empowerment” has pervaded contemporary American culture. The term has been applied by social workers and scholars in the areas of psychology, public health, and community development[43 44] to identify the granting of power to both individual and dependent groups in securing self-determination. As an integral facet of community psychology, empowerment has been viewed as the mechanism by which people and organizations: (1) gain control and mastery over their lives[45] and (2) maintain autonomy within a community that enables the representation of one's own interests.[46]

Perkins and Zimmerman pinpoint "health empowerment" best when they argue that it is an intervention that links "individual well-being with the larger social and political environment."[47] Health empowerment is the overcoming of the feeling of powerlessness with regard to one's health—it is the ability to muster self-help in ways that can direct one's destiny toward healthy lifestyle outcomes. As such, health empowerment is a construct that links individual strengths and proactive behaviors to a culture of health and social change.[48,49] Health empowerment also means patients and healthy lifestyle seekers acquire well-being through participatory medicine—where mHealth technologies deliver remote self-monitoring, with less dependence on brick-and-mortar healthcare. This, of course, is a major paradigm revolution for physicians, where a shifting of power and control over patient health is transferred to the individual and their community or health network.

Concurrently, social media is becoming the new health exchange, while patient-centered information networks are on the rise, and transorganizational communities, made-up of individuals and healthcare organizations, are increasingly supporting the collaborative efforts of patients, doctors and hospitals in ways to advance HLM. And, at the center of this new healthcare model, mHealth is empowering patients in engaging ways that promote collaboration with personal health practitioners and uses personal health data and advanced analytics to help put health information into context in the decision-making process of treatment.

The growing demand for a broader spectrum of mHealth tools focused on HLM represents a significant opportunity for the clinical specialists who focus on NCD. Moreover, mHealth can more readily offer a healthcare ecosystem to support a *culture of health* in tandem with a mindset that challenges old paradigms about access to personal health information, products and services. As a sign of greater movement toward personal HLM and community engagement, expectations of both laypersons (patients) and power consumers of mHealth technologies will increase.

Effective Sociotechnical Models that Support mHealth for HLM

Putting the impact of engaging mHealth and patient-provider collaboration in real-world context demands that a conceptual framework be used to adequately capture the complexities of healthcare and HLM. Indeed, a seminal review of CHI research concluded that although these eHealth technologies (e.g., home monitoring, cell phone, video, telemedicine, online support groups, the Internet, etc.) may be beneficial for health and disease management, they are limited by issues related to misalignment between the technology used and the users' sociotechnical environment.[50] In particular, the report uncovered barriers such as inadequate integration of the health IT into people's lifestyles, lack of trust in the system, usability problems, and misfit between the technology and people's attitudes or abilities. Valdez and colleagues argued these barriers stem from an inadequate understanding of the sociotechnical system and activities of the intended end-users of those respective healthcare technologies on the part of system designers and implementers.[51]

For this reason, we looked to sociotechnical systems theory (from human factors engineering), which supports a better understanding of end-user performance, i.e., the optimization of interactions between complex human/social behavior, activity and technical, environmental, and organizational structures and processes. Such work has included the modeling, design, and implementation of computing systems that support clinical work and personal eHealth applications. Biomedical and health informaticians, clinicians, and healthcare researchers have increasingly acknowledged the significant contribution of sociotechnical systems modeling to better grasp the complexities of human-to-human and human-to-technology interaction in both personal and work environments.[52,53,54] Human factors engineering has contributed several sociotechnical models in the fields of HI and health services research. One well-known example is the SEIPS 2.0 model, which was specifically designed to account for patient engagement in consumer health IT. (See Figure 2.) The model describes three interacting components:

Work System: Work system as a structural entity comprised of interacting components such as person, tools, tasks, organization, and environment.[55] The model places the person(s) in the center, symbolically, to encourage system design to accommodate people or groups.[56] The work system structure is modified to, among other things, identify both patients and healthcare professionals as key people in the work system.

Processes: The interacting work system produces processes, which can be classified as care-related and non-care processes or as cognitive, physical, or social-behavioral. The model recognizes three types of work processes: 1) professional work, in which patients and families are not actively involved, 2) patient work, in which healthcare professionals are not actively involved, and 3) collaborative patient-professional work. Collaborative work represents activities in which professionals and non-professionals work in concert, for example, patient-clinician communication, family-centered pediatric rounds, or weight management comprising a combination of clinical therapy, personal care, and assistance from specialists such as personal trainers, dieticians, or physical therapists.

Outcomes: Processes, in turn, produce outcomes for the patient, provider, and organization. The model has been used across healthcare domains and in particular for studying HI. The SEIPS model also elaborates on the patient, professional, and organizational outcomes produced by these types of work, which can be distal or proximal and desirable or undesirable.

Recent applications of SEIPS 2.0 elucidate the "patient work system" or the factors shaping patient and collaborative patient-professional work.[57,58] Of interest, these studies identify a variety of factors uniquely influencing patient behavior, such as patient functional ability, caregiver capacity, therapeutic side effects, absence of tools, social influence, lack of financial resources, and weather. Such studies are capable of informing specific interventions or producing generalizable design implications that can impact the engagement of mHealth technologies.[59]

An assumption of SEIPS 2.0 is that patients and other nonprofessionals perform *work* or *life's effortful activities* towards a goal.[60] Patient work is a concept originating in social science, where three interrelated lines of work were proposed: illness-related (e.g., taking insulin); everyday life (e.g., grocery shopping); and biographical (e.g., crafting a new identity as a diabetic patient).[61] In recent applications of the patient work lens, researchers have noted that unpaid patient work is burdensome but invisible to outsiders.[62] As a result, it may go unsupported, and therefore needs to be better understood at every stage of the technology design lifecycle.[63] Further, (per the SEIPS 2.0 model) patient work informatics experts advocate not only the development of consumer-facing technologies for patients but collaborative technologies to support patient-professional collaboration.

FIGURE TWO PIC PLACED HERE.

Fig - SEIPS 2.0 model depicting the sociotechnical work system, performance processes, and outcomes with the adaptation and feedback loop mechanism. (Adapted from Holden RJ, Carayon P, Gurses AP, et al., 2013)

Applying SEIPS 2.0 to Diabetes mHealth Design

According to the Centers for Disease Control and Prevention, by 2012, an estimated 18.8 million persons in the US had been diagnosed with diabetes mellitus and another 7 million had undiagnosed diabetes.[64] According to WHO, the number of people (worldwide) with diabetes Mellitus (Type 1 and 2) has risen from 108 million in 1980 to 422 million in 2014, an 8.5% increase in those from 18 years of age and older.[65] Diabetes is a serious public health problem, which has been steadily increasing over the past three decades. WHO notes that diabetes is "one of four priority NCDs targeted for action by world leaders." (p. 1) Adults with diabetes have a two-to-three-fold increased risk of heart attack and stroke. By 2012, over 1.5 million deaths were reported due to diabetes, with an additional 2.2 million deaths being attributable to high blood glucose. [66] The impact of these statistical outcomes has driven BHI and CHI researchers to seek and apply models like SEIPS 2.0 to persons managing type 1 or 2 diabetes. The results have allowed them to better understand several possible interacting work system factors and processes in the context of HLM medicine.

Figure 2 depicts the work system of a hypothetical healthcare work process for a fictional diabetic named Joe. Joe's persona states that he is a 45-year-old single Latino male living in Chicago, who graduated from high school and has a mid-range income. Like other Type 1 diabetics living in the US, Joe does his best to visit his doctor regularly, but struggles with selecting the most nutritious food groups, exercising regularly, and applying other health-centered behaviors that promote a healthy lifestyle. On the other hand, Joe attempts to remain current with his smartphone upgrades and a range of mHealth apps and devices that support his personal HLM.

As noted, the SEIPS model allows us to contextualize the sociotechnical work system for any person (e.g., Joe) with diabetes or any NCD. In particular, the work system is associated with design opportunities emerging from each of the three stages. For example, using the corresponding numbers (1-5 in Figure 2), the Work System outlines five impact factors: **(1)** The design, development, and implementation of mHealth diabetics technologies for managing healthy lifestyles for checking and recording blood glucose levels, nutritional information from food labels and daily meals, and exercise routines. **(2)** Diabetic patient/user(s), close friends and family members, clinicians, social workers, other healthcare professionals, communities and networks—both online and offline. **(3)** General and diabetes healthcare organizations, structures, institutions, and health management systems (both at home, in the community, or in hospitals) provide a supporting infrastructure, including interaction between sociocultural and sociotechnical systems. **(4)** Tasks and task factors (attributes such as difficulty, complexity, variety, ambiguity) are the actions within larger work processes that are the objects that people use to assist in doing work, e.g., using several mHealth apps that provide a cross-section of functionality to support diabetes HLM for diet, medications, and exercise. **(5)** Internal and external environments refer to both the physical ecosystem (e.g., lighting, noise, temperature, air, water, and food quality, and environmental and social spaces) and societal, economic, ecological and policy factors outside a person's immediate community. Both environments have a major impact for maintaining and promoting healthy lifestyles, specifically for diabetic HLM. Other relevant factors within the work system to consider might also include: medical history, current health status, personal skills and behavior, and influences from family, friends, co-workers, personal physician, and the neighborhood and community at-large.

In light of the HLM framework (as applied to SEIPS), particularly emphasis should be placed on the Performance Processes stage, which focuses on these work examples: **(A)** Professional work: (1) Inpatient management of a hospitalized diabetic patient, (2) Drug prescription and adjustments, and (3) Ordering and performing procedures such as surgery. **(B)** Collaborative work: (1) Collaborative treatment planning and (2) Office visit and remote communication, and **(C)** Patient work: (1) Diet, (2) Meds, (3) Exercise, etc.

The Work Outcomes stage is defined as the resulting condition from all work system factors and work processes, including important performance and process indicators, such as adherence to checking glucose levels (proximal) and resulting disease control (distal). Finally, the concept of Adaptation depicts the feedback loops representing intended and unintended adaptations, e.g., problems related to the patient experimenting with a new diabetic diet or exercise routine.

As illustrated in Figure 2, the SEIPS work framework recognizes life's effortful activities within the complexity of the mHealth design process. To deal with this complexity, mHealth researchers and designers follow human-centered design principles and practices[67,68] that align with a user's work system–relative the healthcare problem under study. As demonstrated, Joe's unique HLM work system explicitly shapes the performance of his self-care,[69] including the use of several diabetic mHealth technologies.

Conclusion

In the future, people will play a much greater role in their healthcare, and more broadly, eHealth innovation will empower them in achieving and maintaining a healthy lifestyle, developing healthy communities, and collaborating with healthcare professionals in the management of disease. As the focal point of healthcare shifts to home and community-based settings, the ubiquitous nature of mHealth applications will hold considerable promise for supporting patient self-monitoring and self-care management.

This paper addressed ways that health technology consumers are increasingly moving to HLM to mitigate such health risks, but also to increase engagement and improve patient- health system interactions that establish and sustain healthy lifestyle practices. Through the exponential growth of mHealth those seeking HLM increasingly have the means to control personal health information and healthcare outcomes. An important contribution of human factors engineering to the healthcare domain is the discipline's focus on work systems and its various sociotechnical system models which have accommodated a new framework for studying work done by health informaticians, healthcare professionals and mHealth researchers and designers. As such, we offered SEIPS 2.0 as a useful conceptual model and analytic tool to study complex patient work approaches that support the design, develop and implementation of eHealth technologies and their potential to emerge as consumer-facing NLM products that can support NCDs like diabetes.

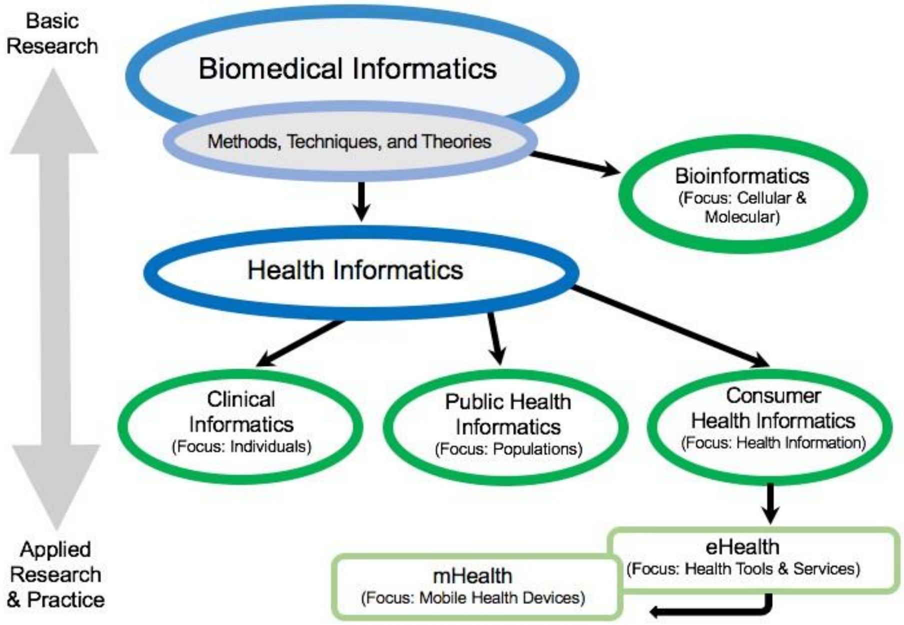

Fig 1- Subcategories of the biomedical and health informatics field, with areas of application and practice, spanning from basic research to applied research. Adapted from Shortliffe and Blois (2006), Kulkowski et al (2012), and Hersh (2009).

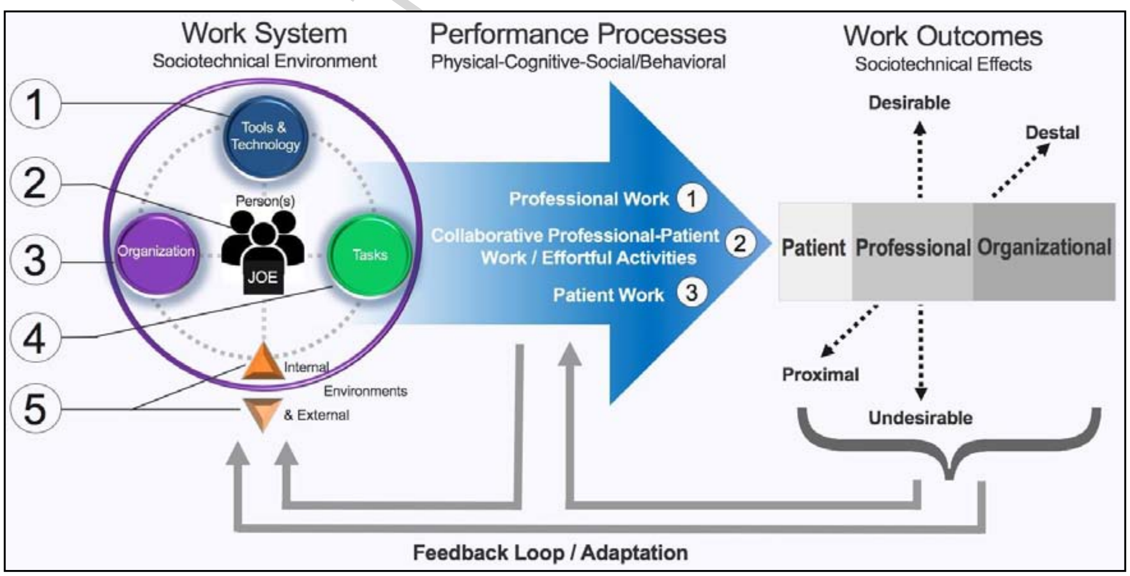

Fig 2- SEIPS 2.0 model depicting the sociotechnical work system, performance processes, and outcomes with the adaptation and feedback loop mechanism. (Adapted from Holden RJ, Carayon P, Gurses AP, et al., 2013)

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