Calling HCI Professionals into Health Research: Patient Safety and Health Equity at Stake

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ABSTRACT

The paper describes the need for expansion of the role of human-computer interaction (HCI) professionals into the field of e-health interventions, including games, virtual reality, and social media. Authors summarize critical practical, methodological, and philosophical gaps that prevent further synergy and collaboration. The necessity for closing these gaps is guided through a discussion on ethics and a health equity framework.

CCS CONCEPTS

Human-computer interaction, code of ethics, consumer health

KEYWORDS

Health research, games, virtual reality, ethics, methodology, patient-centered, participatory, health equity, patient safety

1 Introduction

“Team science[50]” is an emerging research approach encompassing the entire translational continuum[71]. There is now even a Science of Team Science[28] field, which empirically investigates the value of team science and makes recommendations on how to improve such teams. As the field of e-health[18] expands to include more digital interventions, especially those with interactive entertainment features (i.e., games, virtual reality, social media), the role of human-computer interaction (HCI) professionals becomes critical and even more complicated. E-health interventions require accessibility and usability to have any chance at achieving efficacy or effectiveness in health-related outcomes[22]. E-health interventions that include games, virtual reality, and social media features require

potentially a higher standard of entertainment efficacy, as well as greater socioecological validity for both ethical and practical reasons, which will be discussed in this paper.

The authors present some of the gaps in team science that exist between HCI professionals and health researchers that prevent deeper collaboration and synergy from taking place. We will refrain from reiterating the recommendations of good team practices for interdisciplinary team work[49], and from describing systemic challenges and opportunities in interdisciplinary education[30] and communities[66]. We acknowledge that the HCI community is both quite heterogeneous and interdisciplinary.

1.1 HCI Presence Across the Entire Healthcare Product & Service Lifecycle

Current failure to conceptualize healthcare as both product and user experience across the entire lifecycle presents an opportunity for HCI professionals to contribute to potential health outcomes. There is, however, some confusion over the role of HCI professionals in the design lifecycle of products and services in general: where do HCI professionals fit in—before design, during design, during early evaluation, or at the end (and what is the end)? Ideally, HCI expertise should be included from beginning to end, but HCI professionals are themselves quite specialized; thus, different types of knowledge may be needed at various stages.

This first point may seem obvious to HCI insiders, but outsiders to a field that is fairly new, such as HCI, hold many preconceived notions about skills, methods, and role interchangeability of individuals who operate within the HCI sphere. The first misconception to be cleared is that user experience (UX) is not the same as user research (UR) and HCI expertise is not limited to a “visible” (graphical) user interface (UI). Some HCI professionals are designers, others are engineers or computer scientists, and some are psychologists. When in the same room, aforementioned professionals may know each other’s scope of practice, but the authors would like to raise awareness to the fact that in health research teams these distinctions and boundaries are mostly unknown.

What types of HCI expertise could be contributed at each stage of health research? The expected placement of HCI professionals is during iterative design and testing of a “product” prototype, and

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their role is primarily focused on problem discovery while the prototype is being built. We argue, however, that in health research, early *formative research* activities would benefit from HCI expertise. These activities may include observational studies of competitive products and services, field research, interviews and/or focus groups, which happen prior to designing and building a prototype[25]. HCI expertise is needed right at the beginning of research because HCI professionals can also contribute and shape design directions (and can also provide *summative research* questions) before a single line of computer code is written.

The more well-known iterative design process[20] should be considered a mid-stage research process (e.g., RITE method[44]). HCI professionals must be comfortable working side-by-side with developers and designers to make near real-time recommendations. Why do we make this point? In health research, performing evaluations is done “independently” as a norm to maintain “objectivity.” This approach of separating evaluators from intervention designers is recommended only with a finished product and not in the early stages where the goal is to tailor the user experience quickly and efficiently. Unfortunately, many of these design progression fine points are rarely published and thus it is hard to appreciate all the steps a team has followed to arrive at a specific user experience and product.

During the phase that HCI professionals may consider as *summative research*, (a.k.a. piloting and feasibility studies), HCI experts can measure engagement, usability, and entertainment efficacy before conducting larger clinical trials. Sample size should not be used as a rationale to determine what type of study can be conducted because opinions here differ among HCI professionals[38] and even for biomedical researchers[8]. The teams must remain focused on expected outcomes to power studies appropriately. This transitional stage where usage (a.k.a. engagement) may lead to some health behavior change, requires thoughtful study design to include safety and quality measures critical to ethical and replicable larger-scale studies[23].

Should HCI professionals be included in randomized controlled trials and pragmatic trials[54]? Absolutely, because they can provide metrics of core variables (i.e., engagement, usability, and entertainment efficacy) that could be critical mediators or moderators of behavior change. There is a need here for different types of HCI expertise: big data, complex statistical analyses, and qualitative research for sub-sampling of large studies to help contextualize findings in reports. HCI insights may be critical to the success and sustainability of a health intervention.

1.2 Climbing the Tower of Babel

The design and evaluation of health-related interventions are becoming increasingly more inclusive of researchers and practitioners from diverse fields. The issues discussed in 1.1. glossed over the frustrating differences in “vocabulary” and naming conventions for various study research phases. For example, the distinction between *formative* and *summative* stages of HCI research is not well understood, and there are many epistemological differences between social and clinical sciences

about such naming conventions[38]. The reader of this paper may disagree on what is a pilot vs. a feasibility study, on what happens before, during or after a usability study, on whether usability outcomes are primary or secondary outcomes, on who is included in participatory research (see 1.4), on when ethnography is needed, and on the differences between a use case scenario vs. user experience. These issues will not be resolved in this paper.

Transdisciplinary research is probably the most advanced form of interdisciplinary collaboration. It requires team members to work together from beginning to end and to define, redefine, and agree on joint processes and methodologies under a united front goal or philosophy. Holley [30] explains that “unlike other forms of knowledge production, transdisciplinary work examines how boundaries (...) can be eliminated in an effort to engage knowledge across multiple sites. The focus of transdisciplinarity considers the engagement of different academic disciplines and practitioners in solving real-world problems.” It is important for a team to reach a consensus on the purpose and value of a particular method, to break out of disciplinary conventions and to decide on these matters together. This is the only way to conquer the potential Tower of Babel.

1.3 The Danger and False Promises of “Recipes”

As fields of research and practice advance, the need to replicate and scale processes is inevitable. This need stems from a deep-rooted desire to manualize design and evaluation processes, sometimes without enough appreciation for the dynamic aspects of creativity, as well as contextual variables, such as the environment. Valuable workflows[48], heuristics[23, 35], and other formats[15] have emerged in the field, but all of these should be understood as post hoc “recipes.” This means that there can be no substitute for the necessary human talent and charisma (especially for data collectors and interviewers) within a team that executes such activities.

Research leaders should understand that small changes in contextual variables can produce very different results. This outcome also needs to be explained in funding proposals to sponsors and investors who are risk-averse and who demand the use of “evidence-based” processes that can guarantee good results. We should all beware of guaranteed results because this type of promise makes a mockery out of the empirical nature of design and research and reduces the risk tolerance of sponsors and investors. Using well-known systematic methods does not guarantee anything except sanity and efficiency (and even here we cannot expect 100% success).

1.4 Participatory Design & Research Absentees

Participatory design is required in health research, but the relevant skills are not well developed in health care researchers. Adding to the Tower of Babel introduced in 1.2, *participatory design*[14, 47], *participatory health research*[68], *co-design*[6], and *community-based participatory research*[76] often get confounded, which is understandable because they have considerable overlap. The authors intentionally do not separate design and research (or evaluation) as distinct processes from the

beginning of this paper because these types of separations have not served health research very well. Sponsoring agencies are rarely prepared to bear the cost of the entire design and research lifecycle and are not always aware of the return on investment benefits. In health research, the current trend of using the term “patient-centered” adds another level to the Tower of Babel for HCI professionals to climb. Who participates in the *user-centered* vs. *patient-centered* design and research processes?

Healthcare includes a wide variety of stakeholders who all make critical contributions: recommenders, buyers, prescribers, operators, maintainers, researchers, patients, the patients’ family, clinicians, other caregivers and more. If these stakeholders do not participate early on in research, results can be devastating. In general, the need for “participation” in health research is driven from ethics and the desire to understand and represent the needs of vulnerable populations[31, 73]. Unfortunately, not enough is published about the wide circle of people who are needed to make something succeed and how to improve sampling of stakeholders. The term “community” is often added to “participatory research” and has both political and epistemological implications. What happens when “participation” fails?

The electronic health record (EHR) is an example of one of the most shameful (and often unacceptable) user experiences [16, 58]. The absence of HCI professionals in healthcare has resulted in EHRs that have been designed without basic regard for user experience as if the entire field of usability research never existed. This predicament has plagued these critical, and often government-mandated informatics systems that are supposed to provide safety and quality for all patients. Even more infuriating to the authors are requests to “gamify” or provide “aesthetic” improvements on such systems that are so heavily bottom-up engineered that their functionality is near impossible to improve.

Unfortunately, the benefit and diversity of HCI expertise are not so evident in funding decision-making circles. For this to improve, HCI professionals need to be more outward focused and actively participate in healthcare research and development to promote participatory design and research methods. The authors have observed dominance of clinicians and engineers in the top hierarchy of team science and a minimal and naïve conceptualization of stakeholders. Aggressive representation by HCI professionals is necessary to educate others on the value of HCI methodologies and the perils of its absence.

1.5 Design Equals Policy-Making

Unbridled design-thinking has resulted in lasting policy-making impact in many fields including health. In the absence of advanced “participatory” methods, design-thinking privileges the designer (i.e., product, feature, experience or software designer) with making decisions alone—decisions that could have lasting health consequences if the design is successful. Iskander[12] brings up the example of specific failed products, such as water pumps, mosquito nets, and shoes. The 2018 World Usability Day theme “Design for Good or Evil”[1] brings up examples in healthcare, such as packaging scalpels. Given HCI’s tradition originating much in the ergonomics field (and not so much in

psychology), many examples of design-thinking impact are tangible products. In healthcare, we brought up the EHR as an example of software where the dichotomy of “good or evil” can certainly be applied. The policy-making impact of the EHR is not so obvious because many design-based solutions originate from organizational or legal policy decisions. Let us stick with the EHR example for a moment. A government or organization establishes a policy that requires the implementation of an EHR (often for legal and financial reasons). They may build an EHR system from scratch or purchase one from a vendor. Decisions-makers who lack technical expertise along this path inadvertently “buy into” policies unbeknownst to themselves.

EHR designers are also part of this policy-making path because their user experience becomes the norm making them responsible for requiring certain behaviors. From too many “mouse-clicks” to the wrong “mouse-clicks,” such behaviors affect the health and safety of patients[57] and even EHR operators (e.g., repetitive injuries). This last point addresses how software design and user interface may have both real-time and long-term impact (i.e., how data is collected for the mandated “meaningful use” standard [3]). From the standpoint of achieving health equity, capturing social and behavioral determinants of health within the EHR is a matter of policy and HCI professionals could be ones to advocate for such features assertively.

1.5 HCI in Interactive Entertainment & Ethics

We hope that the previous sections convince readers of the need for a wider and more pervasive role for HCI professionals within health research. Besides climbing the Tower of Babel, if HCI professionals will be the ones to provide a bridge across disciplines and to a wider range of stakeholders, they will need to be guided by ethics and a human-focused orientation. Although we mentioned products and user experiences that were health-focused, we would like to expand the discussion into all interactive entertainment-based products and experiences because they are used so pervasively, resulting in lasting positive and negative health consequences. In the past decade, health researchers are increasingly using games, virtual reality, and social media in bespoke interventions for changing health behavior [24, 26, 33, 36, 39, 61]. Other approaches include using existing and widely used entertainment-media for intervention. Facebook, for example, has been piloting a suicide prevention feature for the past year[32]. The impact of this feature is mostly unknown. The field of “gamification” has become a fertile ground for intervention for both good and evil[29, 37, 40, 78]. The impact of such behavioral interventions is still being evaluated[10].

Video games have been a contentious area of research in health for three decades, with a significant bias toward negative impact[7, 27], primarily focused on violence [5, 17, 27], or overuse injuries[45]. The diversification of game genres and makers has resulted in more examples of games that can be used in health targeting physical and mental health outcomes. The opportunity to improve health through the repetition of a pleasurable activity seems at first very noble. Without an ethical framework, however, and without the participation of the right

stakeholders (see 1.4), this area too has fallen under some criticism, especially activities conceived as “brain-training” games[56, 67].

The next frontier of interactive entertainment in health-research is virtual reality (VR)—a medium that has finally matured for scaling in health[62]. Interactive entertainment and related-technology are shifting mindsets [34, 41, 43, 46]. VR has shown strong results and effect sizes in health research, even with minimal immersion and basic entertainment efficacy[11]. The first VR game heuristics in usability research have made their debut[13]. Unfortunately, the long-term impact of VR on health is not known, especially with regard to children and adolescents[41]. Short-term, the “dangers” of VR, including augmented reality[52, 55] are overblown or underappreciated in the popular press. Public opinion varies on who is responsible for these injuries and, in the future, the courts will decide.

Ethical health research is guided by the principle of *beneficence*[59]. Ethical conduct means responding with action when one knows of the potential for negative consequences, working to anticipate and monitor unknown consequences, providing opportunities for informed consent and for withdrawal of consent, and above all, trying to balance risk and benefit consequences of interventions. For example, although VR is typically not recommended for children under the age of 13, in clinical settings there are many examples of brief palliative use of VR for pain in children of all ages. Such experiments are typically supervised and conducted by psychologists and clinicians who understand the risks and benefits of the device and content usage and who are judicious in their use. In pain management, the use of VR in children is seen as low risk and high benefit because the environment is controlled[41, 42].

In general, interventions with games and virtual reality for children and adolescents are in high demand yet receive the least amount of evaluation investment support. Perceived risk for validating such interventions is high, which means few of them are created, and thus health inequity is further increased because of reduced access to such potentially powerful interventions. Now that VR and games are widespread, the public sphere has become a big natural experiment for the impact of interactive entertainment, leaving parents and educators as gatekeepers and moderators of use. Since the “cat is out of the bag” as we say in popular speech and these technologies have left the lab and entered people’s homes and shopping malls, the burden of impact could be moderated by designers and HCI professionals.

For many years, we could use an excuse of “we don’t know” for technology. We have now learned some “things.” Some of these things are not very positive. Very good games can become addicting for people at risk for addiction [19, 63] with a prevalence between 1-9% depending on population sample[21]. Those who are vulnerable are often disadvantaged socioeconomically, genetically, and with adverse childhood experiences [9]. Consider the number of children who play video games in the United States (90%)[21], which has a population of people under 18 around 23% (74 million)[51]. If only 1% are suffering from game addiction[21], 740,000 children and teens

with addiction is a very costly societal problem that affects everyone. It is not impossible to detect problematic gaming behavior; therefore, we anticipate that safeguards could be programmed to minimize the issue of “excessive” use. It is worth noting that the American Academy of Pediatrics has developed a nuanced and practical approach to handling “screen time”[65], which can be operationalized into design practices in the future.

Providing pleasure is a primary goal of interactive entertainment yet mention of addiction often leads to a debate on hedonic value by consequence of successful design. Hedonic pleasure could result in “excessive” use. In health research, providing pleasure is important to promote intervention usage on the (hopeful) path to health-outcomes efficacy. It is also important in a health context to provide pleasure to relieve suffering (if we are guided by compassionate care practices[64]). As for “excessive” use of interactive entertainment applications in healthcare, given the size of our budgets for content creation, we are far from facing this risk. The immediate threat is boredom, and lack of engagement due to low entertainment efficacy[77] as users become more media literate, and they expect higher quality.

The ethical dilemmas that will prevail in the next few years will generate many discussions about “virtuous” pleasure, which has been a matter of debate since ancient times. Epicurus, a much-misunderstood Ancient Greek philosopher, was criticized by other philosophical schools and later by various religious organizations for his support of hedonism[69]. What critics failed to understand in his doctrines was his highly compassionate approach to the pursuit of happiness. Epicurus suffered himself from kidney stones, which ultimately led to his demise (he was not a stranger to suffering). He believed that happiness was “ataraxia”—the absence of “unnecessary” physical and mental suffering. Epicurus also believed that ataraxia could be obtained through “virtuous” (moderated) pleasure while surrounded by like-minded people. Finally, he understood the value of subjective experience and sense perception[74]—concepts often discussed in HCI.

Health researchers and HCI professionals—it is you who will be called on in the future to decide what is “unnecessary” physical and mental suffering and how to “moderate” pleasure. The authors hope that compassion—a mindful action-oriented endeavor[2, 64], which sometimes even calls for inaction or silence[4]—will guide your decisions. We believe (and hope) that compassionate care[64] combined with the strengths of HCI will become the next team science frontier toward achieving health equity for all.

2 Answering the Call to Action

How do you start with health research? HCI professionals can provide advice to help improve research dissemination, knowledge translation, and implementation in other settings. For example, the cultural dimensions of usability, including nationality, are essential considerations for scaling in health intervention delivered via cell phones[75]. Understanding context transfer through higher quality mixed methods research and thoughtful sampling[70] is a great practical challenge in health research. Accelerating adoption and replicating studies in different contexts are all within the wheelhouse of HCI expertise.

As for collaboration language “differences”, they can be resolved early by moving to a transdisciplinary approach in which new hybrid methods can be co-constructed, but this is often an aspirational goal due to budget and time constraints in teams. Building true transdisciplinary teams requires considerable investment in resources—difficult to attain in times of financial crises. If transdisciplinarity is not attainable, teams and individuals can disclose their scope of practice early and establish strong boundaries for robust cross-disciplinary methods[30, 60].

As for recipes for development of products and experiences, remember that they often omit vital details, which are not included for economy of space or because they may be taken for granted. Such omissions are common in research, especially in the social sciences, and the phenomenon has contributed to the replicability crisis[53]. Most scientific publications do not contain all the details of the research protocol due to space and time restrictions. Recipes suffer similarly, but they are just meant to be a reference and a shorthand guide. Regardless, we could use more HCI recipes in the field (and perhaps fewer promises).

In terms of addressing health inequality[72, 76], the absence of HCI professionals who may be the only advocates for vulnerable and under-represented users is a political failure (in the ethical sense). The absence of a discipline that advocates for end-users in health research, either by “omission” or “commission” shows “cultural insensitivity” because health is a human right. In addition, the same diversity and inclusion challenges that apply to potential “users”, apply to all members of the research team, as well as sponsors and/or investors. In research, “representation” is not limited to protected variables, such as sex, gender, race, ethnicity, etc. It extends to disciplinary expertise, which is part of our identity and shapes decision-making.

As technology becomes pervasive, its capacity for “evil” increases when it is implemented without regard for safety and quality. Designers and engineers do not often know enough health psychology, anatomy, physiology or public health to consider the impact of their design decisions. HCI professionals could provide a bridge to these others disciplines over time. Philosophical frameworks and ethical mandates exist to prompt us to ask better questions, but science moves too slowly to provide all the answers we need for “perfect” implementation. We cannot achieve perfection. We can, however, act, design, implement, and evaluate with compassion while pursuing interventions that can promote patient safety and health equity for all[2].

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