

# HCIC Panel Proposal

## The Role of HCI in Translational and Clinical Science: Untapped Opportunities for Broad Social Impact

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### Abstract

Despite huge investments in biomedical research, there is a growing realization that medical breakthroughs often have limited impact on the health of patients. To address this problem, the National Institutes of Health (NIH) has established and provided funding for *Translational and Clinical Science* which aims to encourage the two-way translation of results between basic science research, clinical research, and practice in the medical community. Central to this enterprise is the development and adoption of tools that support interdisciplinary and collaborative research. Unfortunately, while these themes are highly familiar to Human-Computer Interaction (HCI) researchers, the discipline is largely under-represented in one of the most sweeping changes in biomedical research.

To bring attention to this untapped opportunity, this panel brings together four researchers who will discuss three HCI-focused projects funded by the Clinical and Translational Science Award (CTSA) at the University of Michigan. The presentations and subsequent discussion will highlight a major initiative in the biomedical domain, insights on the challenges and opportunities for HCI research and funding, and the potential for broad social impact on the health of millions of citizens.

## 1. Introduction

Despite billions of dollars invested in biomedical research over the last five decades, there is a growing realization that our ability to generate medical breakthroughs far exceeds our ability to apply those results in improving health [1]. For example, ten years after *beta-blockers* had been conclusively shown to benefit the health of patients recovering from a heart attack [2], studies showed that the drug was prescribed to only 62.5% of eligible patients [3]. These findings, and others like them, have motivated policy makers, researchers and practitioners to question whether US citizens have been able to realize maximal returns on the more than \$250 billion that have been invested in the National Institutes of Health (NIH) since 1950.

In 2003, the NIH responded to these challenges by advocating and funding a new strategy called *Translational and Clinical Science* [4, 5]. The goal of this strategy is to break down the traditional silos of basic science research, clinical research, and community practice based on two types of knowledge translation. Translation-1 (T1) research aims to apply discoveries from the laboratory (e.g., genetic studies on animals) to the development of clinical trials in humans; Translation-2 (T2) research aims to apply results from human clinical trials to enhancing the adoption of best practices in the medical community. Additionally, there are ongoing debates on extending the NIH framework to include a third type of translation (referred to as T3), which includes knowledge translation to patient communities and among patients. In the NIH strategy, knowledge translation is expected to be a two-way process, so that results from community practice also affect clinical research, which also affects bench science. The ultimate goal of this strategy is to significantly improve the health of millions of citizens by the rapid translational of research results to practice.

The NIH's vision is supported by a significant reorganization of NIH funding, with specific allocation towards knowledge translation initiatives. NIH has already provided Clinical and Translational Science Awards (CTSAs) to 24 US medical institutions and plans to provide a total of 60 CTSAs by 2012 with an annual budget of \$500 million [6]. Moreover, the momentum of activity surrounding knowledge translation is underscored by the launch of two new medical journals that focus on Translational Science research, further enabling the rapid institutionalization of a new sub-discipline within medical science.

## 2. Untapped Opportunities for HCI Researchers

The knowledge translation vision advocated by the NIH requires that **interdisciplinary** teams of researchers work in **collaboration** to ensure successful **application** of research results to clinical research and practice. An acknowledged central component of these initiatives will be the development of a wide range of effective computer-based tools and methods to facilitate knowledge translation. Such tools

include those that enable analysis and sharing of terabytes of data such as genomic, clinical trial, and tissue sample data, in addition to social networking tools that enable researchers to find collaborators they can trust on critical projects. Importantly, with the exception of the exclusive subject focus on biology and health, HCI researchers have been grappling with almost identical issues for more than a decade. For example, HCI researchers have advocated the use of multidisciplinary teams in the design of systems, and have conducted research to identify principles for distance collaboration. Given this synergy of interests and aims, there are significant opportunities for HCI researchers to apply existing methods and results to the field of knowledge translation, and to discover new strategies that are specific to this exciting new domain.

Unfortunately, many funded CTSA initiatives have neither included HCI researchers, nor have applied HCI methods and theories. Indeed, the development of tools for translational research has been largely carried out by IT staff, physicians, and computer scientists who have little understanding of the broad range of HCI issues critical for the successful development and adoption of computer systems. From an HCI perspective, this represents a huge untapped opportunity for making a broad social impact through the improvement of patient care.

### **3. Panel Proposal and Format**

To explore the opportunities for HCI researchers to achieve a broad social impact through Translational and Clinical Science initiatives, this panel brings together four researchers who are conducting HCI-focused projects funded by the CTSA at the University of Michigan. The panel presentation will consist of two parts: (1) Presentation of three projects that address the needs of key categories of users in the CTSA -- Translational Researchers, Health Providers, and Patients. (2) Discussion regarding the opportunities and challenges faced by HCI professionals who wish to participate in Translational and Clinical Science research and practice.

#### **1.1. Presentations (30 minutes)**

##### ***Project-1: User Needs of Translational Researchers (10 minutes)***

Most medical institutions funded by CTSA face the problem of a rapid increase in the number of online tools (e.g., clinical trial databases), wide disparity in the need and ability to use these tools (e.g., biostatisticians need statistics tools, while geneticists need gene and protein databases), and low awareness of available tools because they tend to be scattered across many different websites. To understand the specifics of such issues directly from the perspective of end users, we interviewed 30 junior and senior translational researchers at the University of Michigan, and used techniques from *Grounded Theory* [7] to analyze almost 1000 pages of interview transcripts. The results led to insights

into the current state of translational researcher needs, which were translated into the design of a web portal using rapid prototyping and feedback from end users. The project initially faced several political and technical challenges, but the results have received widespread appreciation and acceptance at the national level. For example, three other medical institutions under the CTSA are currently exploring the use of our interview instrument to perform similar studies at their institutions, in addition to exploring the generalizability of the underlying framework for the web portal.

***Project-2: Translating Biomedical Data into Decision-Support Systems for Emergencies (10 minutes)***

The rapid identification of toxic chemicals is critical for saving lives in emergency situations ranging from terrorist attacks to chemical plant accidents. Unfortunately, current systems require a large number of inputs before a chemical can be identified [8]. To understand how we could improve the rapid identification of toxic chemicals, we conducted a network analysis of a toxic chemical database to visualize and quantitatively analyze the relationship between 400 toxic chemicals and the symptoms they are known to cause. The results helped to identify regularities in how symptoms overlapped across chemicals, resulting in new algorithms and interfaces that were specifically useful during emergency situations. The designs were refined through collaboration with first responders, and a controlled study has been approved for evaluation of the system with first responders. Furthermore, the design of the system has been generalized to enable the diagnosis of any condition (e.g., genetic disease) based on effects (e.g., genetic markers), through the use of appropriate databases that contain the conditions and effects of interest. The project therefore demonstrates how methods from network science and HCI can be combined to create a system that has the potential to improve patient care.

***Project-3: Knowledge Exchange, Contextualization and Application among Patients (10 minutes)***

Successful online health communities and websites require effective social interaction mechanisms to promote active participation, inspire meaningful discussions, build trust among members, and ultimately lead to beneficial outcomes in the personal lives of participants [e.g., 9, 10]. Unfortunately, these concepts are often overlooked by designers of online health communities, resulting in low adoption of many systems.

To address this limitation in existing work, this project applies principles from HCI to develop and analyze an online community of kidney disease patients. The initial strategy involves engaging trained peer mentors who can proactively provide knowledge, empathy, encouragement, and coping strategies to new patients in the online environment. This approach will then be broadened to enable patients to share their experiences and perspectives with other patients, with the goal of improving their coping strategies and overall quality of life [10]. Furthermore, the project will enable the communication between

healthcare providers and patients, with the goal of encouraging positive patient behavior change (e.g., [11]). This project therefore represents an attempt to apply HCI principles to design T3 applications, with the ultimate goal of empowering patients to cope with their disease.

## **1.2. Panel Discussion (15 minutes)**

Based on their experience derived from the above projects, the panel members will discuss the following questions, in addition to emergent themes:

1. Is Translational and Clinical Science merely an opportunity for applying HCI best practices, or could it also be an opportunity for making fundamental contributions to HCI?
2. How is the concept of Translational and Clinical Science similar and different to other applied sciences?
3. Does the current framework of Translational and Clinical Science (as currently defined by NIH) require significant reformulation to adequately include the entire range of users in the health domain?
4. What strategies can HCI researchers use to convince the medical community of the importance of HCI, and how are such strategies similar or different from those that were used to convince the IT industry to embrace HCI?
5. Where do current HCI theories and methods fall short when dealing with problems in translational science?
6. Are the current NIH funding mechanisms conducive to HCI research, and what kinds of collaboration are necessary for success?

We expect the above panel discussion to be followed by the standard format of HCIC, which consists of a 20-minute presentation by a discussant, and a 20-minute discussion with the HCIC attendees as a whole.

## **4. Conclusion**

The panel presentations and discussions should help members of the HCI community to become aware of (1) the new vision of translational and clinical science that has swept the biomedical field, (2) the largely untapped opportunities for HCI research and funding in translational science, and (3) the potential for HCI researchers engaged in translational science to achieve a broad social impact in the US and across the world.

## **5. Acknowledgements**

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## 6. Message to HCIC Chairs

If this panel proposal is suitable for the program, we are open to extending or modifying the panel to include other researchers who have interest in this theme.

## 7. References

1. Lenfant, C. Clinical Research to Clinical Practice – Lost in Translation? *The New England Journal of Medicine*, (2003) 349(9), 868-874.
2.  $\beta$ -Blocker Heart Attack Study Group. The  $\beta$ -Blocker Heart Attack Trial. *Journal of the American Medical Association*, (1981) 246, 2073-2074.
3. The State of Managed Care Quality. Washington D.C.: National Committee for Quality Assurance (1997).
4. Zerhouni, E.A. The NIH Roadmap. *Science* (2003) 302, 63-72.
5. Zerhouni, E.A. Translational and Clinical Science – Time for a New Vision. *New England Journal of Medicine*, (2005) 353(15), 1621-1623.
6. National Center for Research Resources, NIH. Retrieved on October 19, 2008. [http://www.ncrr.nih.gov/clinical\\_research\\_resources/clinical\\_and\\_translational\\_science\\_awards/funding\\_information\\_for\\_the\\_2008\\_clinical\\_and\\_translational\\_science\\_awards.asp](http://www.ncrr.nih.gov/clinical_research_resources/clinical_and_translational_science_awards/funding_information_for_the_2008_clinical_and_translational_science_awards.asp).
7. Glaser, B.G., & Strauss, A.L. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, 1967, Aldine Publishing Company.
8. Bhavnani, S.K., Abraham, A., Demeniuk, C., Gebrekristos, M., Gong, A., Nainwal, S., Vallabha, G.K., & Richardson, R.J. Network Analysis of Toxic Chemicals and Symptoms: Implications for Designing First-Responder Systems. *Proceedings of AMIA '07* (2007), 51-55.
9. De Souza, C. S., & Preece, J. A framework for analyzing and understanding online communities. *Interacting with Computers, The Interdisciplinary Journal of Human-Computer Interaction*, (2004) 16(3), 579-610.
10. Maloney-Krichmar, D., & Preece, J. A multilevel analysis of sociability, usability and community dynamics in an online health community. *Transactions on Human-Computer Interaction*, (2005) 12(2), 1-32.
11. Boland, P. The Emerging Role of Cell Phone Technology in Ambulatory Care. *Journal of Ambulatory Care Management*. (2007) 30(2), 126-133.