Health Data
Exploration project

Second Annual

Health Data Exploration (HDE) Network Meeting

Abstract Book:

Personal Data Donation

May 17, 2016

TABLE OF CONTENTS

TABLE OF CONTENTS (cont.)

AUTHOR CONTACT INFORMATION

PRESENTING AUTHOR	ABSTRACT	EMAIL
Rasheed Al Kotob	1	ralkotob@ucsd.edu
Clara Caldeira	2	claram@uci.edu
Cynthia Cheung	3	cyc077@eng.ucsd.edu
Chia-Fang Chung	4	cfchung@uw.edu
Gitanjali Das	5	gdas@ucsd.edu
Sarah Dunseath	6	sdunseath@ucla.edu
Daniel Epstein	7	depstein@cs.washington.edu
Lynn Hao	8	lynnhao54@gmail.com
Jina Huh	9	jinahuh@ucsd.edu
Matthew Kay	10	mjskay@cs.washington.edu
Katherine Kim	11	kathykim@ucdavis.edu
Jakob Larsen	12	jaeg@dtu.dk
Christine Voss	13	christine.voss@ubc.ca
Meghan Winters	14	mwinters@sfu.ca
Donghee Wohn	15	wohn@njit.edu

#1 Rasheed Al Kotob

CONNECTED AND OPEN RESEARCH ETHICS – CORE

Collaborators

Cinnamon Bloss, Vincent Chan, Sarah Dunseath, Rebeca Giacinto, Lynn Hao, John Harlow, Araceli Lopez-Arenas, Michelle Takemoto, Camille Nebeker

Abstract

Background: **M**obile **I**maging, pervasive **S**ensing, **S**ocial-media and location **T**racking (MISST) data collection methods introduce new ethical and regulatory challenges for researchers and Institutional Review Boards (IRBs). The Connected and Open Research Ethics (CORE) project, led by an interdisciplinary research team, is working with stakeholders, including IRBs and researchers, to address these challenges.

Objectives: A CORE initiative is developing an interactive web-based platform where stakeholders can engage in discussion via the CORE Forum and exchange dynamic "best practices" on the CORE Resource Library. We are creating a research community where researchers and IRB stakeholders work collaboratively to promote the ethical design and timely review of research protocols involving MISST technologies.

Methods: Formative research methods are being used to engage stakeholders in the CORE design and beta testing process. Six focus groups were conducted with IRB stakeholders in fall 2015 to identify features and functionality of the CORE platform. CORE Network stakeholders are now contributing by collecting and tagging content that will populate the CORE Resource Library.

Analysis/Results: Focus group recordings were transcribed and analyzed. Results indicate a growing demand for guidance and expertise to evaluate research protocols using MISST technologies. Frequently reported challenges included unfamiliarity with MISST technologies and difficulties determining their potential risks to research subjects. Participants were supportive of the CORE concept as a resource to aid in the IRB review process.

Conclusions: We anticipate the CORE Platform will facilitate stakeholder dialogue via its growing Network Q&A Forum and Resource Library. The CORE is a first step in facilitating the ethical design and timely and appropriate review of research using MISST technologies.

#2 Clara Caldeira

LOOKING FOR THE UNUSUAL: HOW OLDER ADULTS UTILIZE SELF-TRACKING TECHNIQUES FOR HEALTH MANAGEMENT

Collaborators

Matthew Bietz, Yunan Chen

Abstract

Background: Self-tracking applications for health management have become popular both in industry and in academia. Half of older adults in the U.S. track health indicators, but only 2% of them use self-tracking technology such as mobile applications and activity monitors. Because this population's tracking practices have not been sufficiently studied, it is not clear what motivates older adults to track for health care, or how their self-tracking takes place.

Methods: We conducted an exploratory qualitative study to investigate older adults' self-tracking practices in order to understand their purposes and needs as potential users of self-tracking applications. We interviewed 18 residents of a retirement community in California, and asked about their self-tracking practices, daily routine, exercise habits, chronic diseases, technology use, and overall approach to health management.

Results: Our data indicate that older adults use self-tracking primarily to look for the unusual, to detect the onset of abnormal changes in health indicators. This purpose differs from tracking to support behavior change or to acquire self-knowledge. Because bodies become more fragile with age, a decline in condition can have serious and lasting effects on elderly people. Self-tracking for the unusual allows older adults to detect and address problems early.

Conclusions: Self-tracking systems that target the health management of elderly users need to support the detection of unusual changes in health. Providing these users with better suited tools could increase the proportion of older adults who use self-tracking technology, and empower them in their own health management.

#3 Cynthia Cheung

CONCEPTUALIZATIONS OF PRIVACY AMONG EARLY ADOPTERS OF EMERGING HEALTH TECHNOLOGIES

Collaborators

Matthew Bietz, Kevin Patrick, Cinnamon Bloss

Abstract

Background: Advances in health technology such as genome sequencing and wearable sensors now allow for the collection of highly granular personal health data from individuals. It is unclear how people think about privacy in the context of these emerging health technologies. An open question is whether early adopters of these advances conceptualize privacy in different ways than non-early adopters.

Objectives: This study sought to understand how early adopters of emerging health technologies conceptualize privacy.

Methods: Transcripts from in-depth, semi-structured interviews with early adopters of genome sequencing and health devices and apps were analyzed with a focus on participant attitudes and perceptions of privacy. Themes were extracted using inductive content analysis.

Results: Interviewees were proponents of sharing personal data to support scientific advancements, however they still voiced concerns, as well as uncertainty about who has access to their data, and for what purpose. In short, they were not dismissive of privacy risks. Key privacy-related findings are organized into four themes: (1) contributing personal data to science; (2) concerns about discrimination; (3) control over personal information; and (4) personal data security.

Conclusion: Early adopters of emerging health technologies appear to have more complex and nuanced conceptions of privacy than might be expected based on their adoption of personal health technologies and participation in open science. Early adopters also voiced uncertainty about the privacy implications of their decisions to use new technologies and share their data for research. Though not representative of the general public, studies of early adopters can provide important insights into evolving conceptions of privacy in the context of emerging health technologies and personal health data research.

#4 Chia-Fang (Christina) Chung

PATIENT AND PROVIDER GOALS AND USING PATIENT-GENERATED DATA IN IBS AND WEIGHT MANAGEMENT

Collaborators

Kristin Dew, Jonathan Cook, Elizabeth Bales, Allison Cole, Jasmine Zia, James Fogarty, Julie Kientz, Sean Munson

Abstract

Background: Patient-generated data is increasingly common in chronic disease management. Smartphone applications and wearable sensors help patients more easily collect health information. However, current commercial tools often do not effectively support patients and providers in collaboration surrounding these data.

Methods: We surveyed 211 patients and interviewed 18 patients and 21 providers who work with irritable bowel syndrome and overweight/obesity to understand their expectations and collaboration practices.

Results: Providers reported using self-monitoring data to enhance provider-patient communication, to develop personalized treatments, and to motivate and educate patients, in addition to using them as diagnostic and adherence tools. Patients also reported wanting to receive better diagnoses and education, as well as to receive credit for their efforts and to have providers understand the difficulty of their conditions. Providers and patients use patient-generated data to support their interaction and collaboration throughout care cycles and self-monitoring stages. However, limitations associated with current systems and workflows create barriers to regular and effective use of these data. These barriers include a lack of time to review detailed records, questions about expertise to review it, and privacy challenges. Current self-monitoring tools also often lack flexibility, standardized formats, and mechanisms to share data between patients and providers.

Conclusions: Variations in provider and patient needs affect tracking and reviewing needs. Analysis of current systems and practices also reveals misunderstandings and privacy concerns about using patient-generated data collaboratively. We reflect on the social nature of patient-provider collaboration to identify design opportunities to better support use of patient-generated data.

#5 Gitanjali Das

ACCESSIBILITY OF APP PRIVACY POLICIES AND TERMS OF USE FOR MINORS

Collaborators

Cynthia Cheung, Joshua Quiroz, Kevin Patrick, Cinnamon Bloss

Abstract

Background: Privacy policies and terms of use are ubiquitous in the digital age. One must agree to the contents of these policies in order to obtain and use nearly all computer and mobile device apps. Such agreements provide legal protection for companies and often describe the ways in which such companies collect, use and sell consumers' personal information. The extent to which consumers are able to comprehend these contracts, however, is an open question. This issue may be of particular concern when agreements pertain to apps that are targeted towards minors.

Objectives: To assess reading level, readability, and word count of privacy policies for apps that are either available to or targeted towards minors.

Methods: Privacy policies for 64 popular apps were collected and analyzed. Readability statistics and word counts were computed. Results were compared as a function of app category (education, social networking, and entertainment) and target consumer age.

Results: The average reading level for the privacy policies was higher than the average reading level of adults in the United States. There was no difference in readability by app category or target consumer age.

Conclusion: Although consumers must agree to app privacy policies and terms of use in order to use digital tools and products, these agreements are not comprehensible by the average adult, let alone minor. Given that companies often collect, use and sell consumers' personal data, it is concerning that the agreements describing these activities are not accessible to most consumers.

#6 Sarah Dunseath

RESEARCH IN THE DIGITAL AGE: EXPLORING THE NIH'S COMMITMENT TO MOBILE IMAGING, PERVASIVE SENSING, SOCIAL-MEDIA AND LOCATION TRACKING (MISST) RESEARCH

Collaborators

Camille Nebeker

Abstract

Background: Researchers are using Mobile Imaging, pervasive Sensing, Social-media and location Tracking (MISST) technologies to intervene with and/or observe personal health behaviors. Studies using MISST methods/tools are raising new challenges for Institutional Review Boards (IRBs) charged with protecting research participants. There is little evidence to guide IRB decision-making leading to inconsistent review outcomes. This study begins to explore the MISST landscape by identifying the nature and scope of studies supported by the National Institutes of Health (NIH).

Objectives: Study aims: 1- explore the scope and nature of NIH support of this research and, 2- identify how MISST tools/methods are used in currently funded research. A high level aim is to conduct a systematic evaluation of how IRBs execute their obligations to both protect participants and facilitate high-quality scientific research.

Methods: The NIH Reporter database was mined to identify currently funded MISST studies using 17 key words and then organized by the technology, purpose and institute.

Results: Results revealed MISST use in research is relatively novel as only 336 of the 61,584 studies funded by the NIH in 2015 used MISST technologies. Of the NIH-funded MISST studies, 23% of funding was allocated to location tracking research, 32% to social media research, 2% to wearable sensor research, 5% to phone/app research, 1% to research using cameras, and 37% to research using multiple MISST technologies. NIH Institutes funding the majority of these studies included: Cancer (n=42), Drug Abuse (n=38), and Mental Health (n=38).

Conclusions: Evolving research practices and methods enabled by technological advances are rapidly changing how research is conducted. This study sheds light on studies using MISST technologies and institutes supporting this research.

#7 Daniel Epstein

PERSONAL DATA IN EVERYDAY LIFE

Collaborators

James Fogarty, Sean Munson

Abstract

Background: We explore how people collect and consider their personal data as part of their busy, complex everyday lives. While many people are motivated to collect data to help them change a behavior, others have more difficulty keeping up the habit.

Methods: We conducted surveys and interviews with over 200 people who are tracking or have tracked their physical activity, finances, or location with commercial tools.

Results: Prior to collecting personal data, people consider which device or tool will be most effective for them to use to track. People often lapse while their tracking, rarely having a complete personal data log. Some people return to tracking after a lapse, often reconsidering which device or tool is most appropriate based on what they learned from their tracking experience. However, others elect not to return to tracking, either because feel they learned enough from tracking or found collecting personal data a taxing process.

Conclusions: Designers challenges in supporting people who stop collecting data temporarily or permanently. Even the most motivated people will struggle to keep an accurate log of their personal data. Our results outline design scenarios in which personal data which might have gaps or be incorrect, and suggest approaches for addressing these challenges.

#8 Lynn Hao

MINING THE NATIONAL IRB FORUM CONTENT TO INFORM THE CONNECTED AND OPEN RESEARCH ETHICS (CORE) INITIATIVE

Collaborators

Nadir Weibel, Camille Nebeker

Abstract

Background: Mobile apps, wearable sensors, and social media create opportunities to collect vast quantities of personal health data that expand the potential for personalized health interventions. This research also introduces ethical challenges that impact Institutional Review Boards (IRBs) and researchers. Potential benefits elicit consideration of ethical legal and social implications.

Study Objectives: This project examines the national IRB Forum posts to: 1- identify conversations focused on **M**obile **I**maging, pervasive **S**ensing, **S**ocial media and location **Tr**acking (MISST) research strategies, and (2) analyzed discourse process and content.

Methods: A preliminary content analysis of the IRB discussion forum (irbforum.org) was conducted to assess discussion content, process and structure. We strategically targeted relevant information by parsing posts with specific MISST-related keywords (i.e., texting, GPS, social media) and then removed confounding terms and overlapping threads. This qualitative analysis produced seven key themes.

Results: IRB Forum member posts include key words of interest indicating questions about social media usage, visual ethnographic methods and use of pervasive sensor technologies. After keyword reduction, we counted 4,199 total marginally MISST-related threads out of 11,379 total threads. Forum layout prevented us from counting total threads within the past year during this preliminary analysis. With access to raw data, we will now create a program to systematically calculate and estimate change in overall percentage of MISST-related threads.

Conclusions: Evolving technologies have clearly impacted research methods, raising new concerns and areas of confusion in IRB language. Even manually surveying recent posts showed increased debate about social media and more specifically, social media as a recruitment tool. Social media has become highly accessible by a wide population, but IRB guidelines have not updated to accommodate these new strategies. The CORE platform should consider providing resources that clarify the extent of usage and how to address specific social media platforms in research protocols.

#9 Jina Huh

MODELING PATIENT RETENTION IN SOCIAL MEDIA

Collaborators

Xiaoqian Jiang

Abstract

Background: Although researchers developed strategies to reduce attrition, conducting research using social media requires new examination that has not been fully explored in traditional modalities of research. Understanding online social behavior and how such behavior relate to attrition problems will help researchers find innovative strategies fit for new forms of internet-based research.

Methods: We downloaded a public online diabetes community to understand how social interaction with other community members associate with sustained participation. We studied the impact of receiving replies from others to the length of staying on the community. The length of stay was defined by the total time between the earliest post and the latest post for each member. We grouped the members into four quantiles of the adjusted reply rate (average number of replies received per each member's post) to correlate length of stay and adjusted reply rate using student t-test.

Results: The median adjusted reply rate for each group was Q1: 3, Q2: 6, Q3: 9, and Q4: 15.4 replies; and the median length of stay was Q1: 2, Q2: 3, Q3: 7.5, and Q4: 12 days (Figure 1). Our results showed significant differences between the four groups of adjusted number of replies received to the length of stay ($p<0.001$). The results show that receiving more replies is significantly associated with members staying longer.

#10 Matthew Kay

DESIGNING FOR USER-FACING UNCERTAINTY IN EVERYDAY SENSING AND PREDICTION

Collaborators

Jessica Hullman, Sean Munson, Shwetak Patel, Julie Kientz

Abstract

Background: People are increasingly exposed to sensing and prediction in health tracking systems (“how many steps did I take today?”, “how much do I weigh?”, “how many calories have I consumed?”). Uncertainty is inherent to these systems and usually poorly communicated, or not communicated at all. In this poster, we describe several completed and ongoing projects related to the modeling and communication of uncertainty in everyday data, including projects examining step count, weight, and self-experimentation. We also describe results from studies on communicating uncertainty in other domains, such as real-time transit prediction and ubiquitous computing, that may be applicable to the health space.

Methods: The methods vary by project. For example, in investigating people’s understanding of uncertainty in body weight scales, we: 1) conducted a qualitative analysis of online reviews of popular scales, 2) interviewed experts in weight change to understand how their clients deal with uncertainty in weight data, and 3) conducted an online survey examining the relationship between understanding of variation and trust in scales. Other studies focused on the precision of people’s estimates of probabilities from different visual encodings of uncertainty, or on eliciting preferences for different types of error in predictive systems.

Results/Conclusion: Across our research, we find that people have a poor understanding of the components of error (e.g., bias and variance). However, improved understanding of uncertainty is associated with improved trust, suggesting a benefit to more effectively communicating and explaining uncertainty. We propose several methods for presenting uncertainty, and discuss several evaluations of these methods.

#11 Katherine Kim

PERSONAL HEALTH NETWORK: PERSON-GENERATED DATA TO IMPROVE CHEMOTHERAPY CARE COORDINATION

Collaborators

Janice Bell, Richard Bold, Andra Davis, Victoria Ngo, Sarah Reed, Thomas Semrad, Jill Joseph

Abstract

Background: Cancer is a top concern in the United States and globally. Cancer care suffers from lack of coordination, silos of information, and high cost. Interest is emerging in developing formalized coordination mechanisms to address these challenges. Person-centered technology can improve coordination, thereby improving the lives and health of individuals with cancer.

Methods: An inter-professional team developed the "personal health network" (PHN), a new solution leveraging social networking and mobile technologies, The PHN integrates person-generated data related to clinical concerns, medication use and symptom management with a shared care plan and educational materials for individuals undergoing chemotherapy. The PHN was implemented as part of a two arm (n=60), randomized, pragmatic trial of care coordination at UC Davis Comprehensive Cancer Center. Participants received a tablet and a 4G data plan along with care coordination encounters every two weeks. Interviews using think aloud methodology were conducted with the first 12 participants from the intervention arm.

Results: Early results suggest that participants feel more connected to the healthcare team using the PHN, find value in access to the patient education library, and are better able to organize the many activities that occur during chemotherapy. Improvements are needed in reconciling overlaps with information in the UC Davis MyChart patient portal, clarity of navigation and locating specific functions, and inconsistent connectivity.

Conclusions: Person-generated data is a promising source for improving cancer care coordination. Usability findings will contribute to improvements in subsequent versions of PHN. This study contributes to a roadmap for technology-enabled care coordination.

#12 Jakob Larsen

WEARABLE, DIGITAL INSTRUMENTATION FOR BETTER QUALITY DATA ON SUBJECTIVE EXPERIENCE IN HEALTH RESEARCH

Collaborators

Thomas Christiansen, Tomasz Kaminski

Abstract

Background: Obtaining reliable, self-reported data based on memory recall or paper diaries is a well-known problem in health research. Present instruments used for experience sampling (ESM), ecological momentary assessment (EMA), and ambulatory assessment (AA) impose limitations on acquisition of data. Even smartphone apps suffer from being time consuming and requiring many steps to input even simple observations of daily life. We suggest that instrumentation for capturing valuable, self-reported data using wearable technology will not only lead to better quality data but enable a new kind of data on subjective experience.

Methods: We have conceptualized and developed initial prototypes of wearable, digital instrumentation for the capture of subjective experience through discreet micro-interactions. Figure 1 shows smartwatches as example wearable devices for recording subjectively perceived phenomena. Customizable and directly accessible buttons enable the user to quickly record an observation using a single touch gesture.

Results: Initial experiments using smartwatches for acquiring data on subjective experience have demonstrated data acquisition at least four times faster compared to smartphones. Further, the authors have successfully tracked itching of eczema (TBC) and sneezes (JEL) using the prototypes continuously for 7-18 weeks.

Conclusions: While initial experiments with our prototype smartwatch instruments have demonstrated reduced data acquisition time compared to smartphones further experiments with applications in health research are needed.

#13 Christine Voss

USING WEARABLES TO UNDERSTAND SEASONAL VARIATIONS IN CHILDREN'S PHYSICAL ACTIVITY

Collaborators

Paige Dean, Kevin Harris

Abstract

Background: Seasonality affects children's physical activity (PA), which frequently confounds effective research designs and program evaluations. Long-term continuous PA monitoring is needed to truly understand the influence of weather, daylight hrs and holidays on children's PA, but research-grade accelerometers have limited battery-life and memory. We explored weather commercial wearables are a feasible solution to this research problem.

Methods: Participants were pediatric patients recruited from specialist cardiology clinics across British Columbia, Canada (n=26, 14±2.7 yrs, 54% female). They wore a FitBit Charge HRTM monitor for 4-months (Sep/Oct '15 to Jan/Feb '16) as part of a larger trial. Data were extracted through Fitabase©. We liberally defined a valid day (i.e. a day on which the FitBit was worn) as ≥1,000 steps/d. We obtained historic climate data from the Govt of Canada, and used multi-level regression to assess the role of weather on steps/d over time.

Results: Most completed the study (n=2 withdrew, n=4 non-compliant). Participants wore the FitBit on average 6d/week, yielding 1,999 valid person-days of data. During the study, daily steps significantly declined by 94 steps/week; however, mean temperature and snow on the ground, which ranged from 55 to 7° F and 0 to 11in, respectively, explained these declines in PA.

Conclusions: FitBit devices proved popular and useful to monitor PA in children over a prolonged period of time. However, loss of detailed data due to infrequent syncing and the lack of a device-based wear-time metric potentially restrict their use in research.

#14 Meghan Winters

BIKEMAPS: CITIZEN WEB-MAPPING FOR SAFER CYCLING

Collaborators

Trisalyn Nelson

Abstract

Background: Cycling is a healthy travel choice. However, the primary barrier to increased cycling is the real and perceived risks of injury. Data on cycling crashes are limited. The sources we rely on – insurance claims and hospital records –capture only reported incidents with motor vehicles, or where people seek medical care. Comprehensive data is required to assess safety and risk, to identify priority locations for traffic safety interventions and to monitor impacts.

Purpose: We developed BikeMaps.org, a global crowdsource tool for mapping cycling incidents, with the aim of making cycling safer through better data. We aim to generate new information on bicycle safety using crowd-source technology that supports citizen-driven data collection.

Methods: BikeMaps.org is built with free, open source tools. The web- and app-based system allows citizens to quickly and anonymously report cycling incidents including collisions, falls, and near misses.

Results: Since the October 2014 launch, citizens have mapped over 2300 incidents in 30 countries. The website can generate personalized reports on safety for citizen defined riding areas, providing tailored information directly to individual riders. Similarly, it can create regional reports for decision-makers and advocacy groups interested in cycling safety surveillance. BikeMaps.org data enables an exploration of space-time patterns on crashes, near misses, and other safety hazards.

Conclusion: Long-term, our aim is to apply spatial analysis to citizen-generated cycling safety data to develop new knowledge for decision making. BikeMaps.org is designed as a mechanism for data collection, but is also a tool for cycling promotion through citizen engagement.

#15 Donghee Wohn

BREAKING HABITS WITH A WEARABLE SHOCKING DEVICE

Collaborators

Sona Patel

Abstract

Background: Everyone has undesirable behaviors that they want to get rid of. In order to help them get rid of their bad habits, people spend a lot of money on things such as therapy and self-help books. Habits are often associated with an existing routine task, repeated enough times to become a routine behavior, and relies on positive reinforcement. Eliminating a habit thus requires a change of environment and developing an aversive association with the behavior (punishment). Currently, there have been a growing number of applications designed and developed to help people form positive habits. However, not much work has been done with getting rid of habits.

Methods: We conducted interviews (N=15) with users of a new habit-cessation application. This application involves a wearable computing device that delivers electric shocks to people whenever they are engaging in undesirable behavior.

Results: Like most mobile applications that rely on quantified self-mechanisms, we found that the device was successful with people who were highly motivated to begin with. We also found that helping people understand the “science” of how the device can help them encourages usage that results in positive expected outcomes.

Conclusion: Since habits are often non-conscious, many participants wanted to give other people control of the app to deliver the shocks, suggesting that like traditional interventions, mobile habit cessation devices may require a community approach.