This forum is dedicated to personal health in all its many facets: decision making, goal setting, celebration, discovery, reflection, and coordination, among others. We look at innovations in interactive technologies and how they help address current critical healthcare challenges. — Yunan Chen, Editor

‘Nothing About Me Without Me’— Investigating the Health Information Access Needs of Adolescent Patients

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Advances in computing technology continue to offer us new ways to learn about our health and well-being. As mutually reinforcing trends make the use of mobile and wearable devices routine, we now collect personal health-related data at an unprecedented rate. Meanwhile, electronic health record (EHR) systems keep evolving. These systems will allow us to store and manage data describing countless dimensions of our health—from data generated both in clinical settings and in everyday life.

To be effective, healthcare systems—technical and sociotechnical—must be safe and trustworthy. They must build confidence, promote the appropriate level of patient autonomy, and foster positive human–human interactions (e.g., effective patient–clinician communication). To meet these goals, patients and families must be included in care decisions and supported in gaining access to their personal health information. In 1998, Valerie Billingham summed up the importance of patient inclusion in care with her ingenious phrase, “Nothing about me without me” [1]. How we support access and inclusion is an important area of HCI research because, in most cases, we must go beyond simply making health data available.

In pediatric and adolescent care, we need to think carefully about data access and its relationship to patient participation in care. The capabilities of health technologies today often do not cohere with the needs of adolescents or

their family members. To understand why, it is important to note how adolescent health is changing: In the past, supporting teen health meant teaching teens to avoid things like smoking, drinking, and other risky behaviors, and instead cultivating healthy sleep, diet, and exercise habits. With chronic conditions on the rise [2], it is important to reconsider what self-care means—we need to think much more about *illness management*, not just *prevention*. This means that we need to design technologies that enable teens to navigate their healthcare with their family members, while also respecting their need for privacy and confidentiality.

The Health Experience and Applications Lab (Hx Lab) at Georgia Tech is pursuing answers to questions about how health information technology can be designed to enable teens and young adults to become active participants in their healthcare. Over the past four years, we have developed collaborative partnerships with patients and their family members, as well as pediatric clinicians, informatics

researchers, and health IT leaders. With these partners, we have conducted field studies, design studies, and prototype deployments and evaluations, as well as mixed-methods studies that examine the use of current health IT systems. These ongoing and long-term efforts provide insights into three objectives for computing interventions that support teens’ participation in their care.

SUPPORTING GRADUALLY EVOLVING CARE PARTNERSHIPS

The first objective comes from our investigations into how teens with chronic illnesses work with their parents and their clinical caregivers to manage their personal health information. Adolescent users of computing technology are in the unique position of being emerging adults who are still dependent—challenging the single-user paradigm of personal data management we often see today. There are biological, psychological, and sociocultural components to adolescence, making it difficult to place boundaries on when it begins and when it ends. We learned that supporting both teens and parents in acclimating to the role of partner in teen care is essential to aid in the transition to adulthood [2].

Teens in our study often grappled with issues of data privacy, health literacy, and emotional preparedness while tracking indicators of their health. They often found information to be either too difficult to understand or not comprehensive enough to be helpful. A current research project in our group, led by Matthew Hong, is now investigating how technology can

Insights

- When designing health technology for adolescents, one must consider their unique privacy issues.
- It is important to effectively incorporate the perspectives of the individual as well as the family in the design process.
- Providing access to accurate and comprehensive medical information while protecting adolescent patient confidentiality is a significant, open challenge.

capture the perspectives of teens with chronic illnesses as well as those of their parents, in ways that support their voices in clinical scenarios and enable the adaptive presentation and sharing of health information. We are designing our tools to support the collaborative generation and management of personal health-related data.

INTERACTING WITH ELECTRONIC HEALTH DATA

The teens and parents we have partnered with are optimistic about the role of computing technology and EHRs in their care [2]. While we might expect that teens will have different preferences from their parents for interacting with this data, current personal health record technologies (such as patient portals) do not offer different designs for different user groups. Our team investigated independent and shared experiences of online personal health record technology over a 19-month period. We analyzed usage logs and conducted surveys and interviews with teen patients and their parents, independently.

We found that teens and their parents both valued the technology but had divergent views about its role in care communication and management, as well as divergent attitudes about its impact on the patient's ability to manage care. Adolescents indicated a slightly more positive attitude toward the use of the technology to help them manage information about their health and ask questions they would otherwise not have known to ask [3]. Families used health record technology as a coordination tool, even though these systems weren't designed with family coordination in mind.

Teens and parents in our study found personal health record technology to be important, in part because the teens frequently underwent diagnostic imaging scans (e.g., CT, MRI) whose results are shared in the clinic and online. Still, they found that reports of imaging studies were typically not comprehensible. Our research team drew upon analyses of patients' and family members' questions about diagnostic imaging procedures and results, and conducted text analyses of a large corpus of radiology reports.

Cancer patients at Children's Healthcare of Atlanta review results of their diagnostic imaging tests with parents and oncologists, using tools developed by the Hx Lab.

We complemented these methods with user-centered and participatory design to create diagnostic reporting tools that automatically generate abstracted, visual explanations of anatomical concepts and support the collaborative review and communication of diagnostic data. In a pilot deployment study, pediatric patients, parents, and clinicians interacted with the prototype to discuss the patient's current CT or MRI report during a clinical oncology consultation [4].

The prototype helped teen patients keep track of follow-up instructions and notes. Interestingly, we also found that interaction with the digital report often led to dynamic interspersing of report interaction and patient-led discussions. Discussions that started with a focus on digital information often led to rich human-human communication in the clinic: Patients and parents

used the prototype to identify questions to ask about symptoms, the disease process, and treatment, all of which enriched communication.

BALANCING ACCESS TO AND PRIVACY OF MEDICAL INFORMATION

While our studies examined access to particular types of health data, we must keep in mind that our research partners represent a limited set of conditions and family situations. A lot of clinical data, including diagnosis codes, medications and other therapies, appointment histories, and visit notes are generated throughout the course of pediatric patient care. System designers cannot assume that making all of this data available to the family is in the best interest of the patient. Being able to provide access to accurate and comprehensive medical information while protecting patient confidentiality

is a significant, open challenge. Although there are privacy issues to consider for all patients, adolescents have additional, unique privacy needs: Their autonomy is increasing—developmentally, socially, and legally—and they have potentially sensitive health needs.

Privacy laws vary worldwide—and at the state level in the U.S.—and are sometimes ambiguous about whether adolescents can control personal information. In the U.S., most state laws were written before electronic personal health records were routinely accessible to patients. Direct, automated information reporting means that care providers no longer serve as the only information conduits between parents and patients and medical data. These factors create a complex backdrop for the design and implementation of EHR systems, prompting the need for advancements in policy.

In 2017, a collaborative effort between GT Interactive Computing and Cornell Medical explored institutional policies surrounding access to the electronic health records of adolescents in the U.S. Within a sampling framework that ensured the diversity of geography and medical organization type, we engaged with chief medical information officers (CMIOs) and other health IT administration executives across the country, at centers that both serve pediatric populations and have EHRs deployed to manage patient data.

Through multiple studies to characterize the diversity in policies governing access to these records, we found different degrees of adolescent access (from none to partial to complete), access ages (from 10 to 18 years), degrees of parental access, and types of information considered sensitive [5]. Important factors in the decision process about adolescent and parental proxy access included: technology capabilities of the EHR platform, differing patient population needs, human resources, community expectations, and the need to maintain a delicate balance between promoting autonomy and promoting shared decision making with the family. Finally, we found that tensions between teen privacy needs and parental preferences led many organizations to simply disable

all access—for both adolescents and parents—during a patient’s adolescent years. Though this decision was made in the interest of patient safety, for families relying on co-management of complex health situations, we found that loss of access to health records has significant effects on patient health management.

More research in this area is of immediate and serious importance. We will need to be cautious as we go about it, accounting for the potential negative impacts of our research approaches [6]. For example, researchers must ensure that they accurately represent teen perspectives instead of relying on proxies, and will need to avoid leaving behind the voices of historically underrepresented groups.

LOOKING AHEAD—WHERE SHOULD WE GO?

We are entering an era in which more and more control of data and medical decisions will be distributed in multiparty configurations that include patients and their clinical and family caregivers, and numerous computing systems. We will need to prioritize trust, transparency, and safety in system design, in both clinical and everyday settings.

Research on new types of design engagements will be especially important to effectively incorporate the perspectives of both the individual and the family as a unit. Researchers conducting participatory design in this domain must pay attention to unequal power relationships when involving families and clinicians, and capture accurate representations of the patient experience in ways that minimize burden while amplifying patients’ voices. As intelligent systems continue to evolve, decision-making and task-planning solutions will work best when they accommodate the needs of multiple people in fair and intelligible ways that promote appropriate levels of human autonomy, privacy, and confidentiality.

The ethics of providing healthcare has always required that we empathize with the particular circumstances of others. HCI can play a vital and transformative role in the future of healthcare by grounding computing advancements in an understanding and

appreciation of the needs and concerns of the actual people who rely on healthcare—the people for whom our computing tools are being developed.

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ENDNOTES

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