DIY Diabetes Technology in the Nightscout Community: An Ethnographic Study

Abstract
Nightscout is a DIY (do-it-yourself) community of people living with T1D who hacked an FDA-approved medical device in order to access personal medical data for the purposes of better managing Type 1 diabetes. Drawing on an interview study, as well as corroborating data that includes a 12+ months of ethnographic observations, our work describes the mutual shaping of a remote monitoring system designed to display blood glucose values and its community of developers and users. As the first widely deployed DIY biofeedback system, our study of Nightscout explores novel uses of personal health and wellness data by health technology innovators and highly engaged patients. Our work also suggests research directions for several developing HCI research areas—personal informatics, citizen-based biomedicine, and DIY/making/hacking.

Author Keywords
Diabetes; artificial pancreas; DIY making cultures; hacker; open-source; chronic illness; self-management; self-care technology.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.
Introduction

Type 1 diabetes (T1D) is a serious autoimmune disease in which a person’s immune system attacks and destroys the insulin-producing cells in the pancreas. As a chronic condition, T1D is currently unpreventable and has no cure. The management for T1D is often physically and emotionally challenging, both in regards to the risk of serious health complications, as well as the fatigue, anxiety, and frustration associated with daily medical care. Blood-glucose (BG) levels are routinely checked throughout the day and night and measured with a blood glucose meter. Doses of insulin must then be precisely balanced—by multiple daily injections or a continuous infusion through an insulin pump—with everyday activities like eating, exercise, and sleeping. Even with vigilant monitoring, people with T1D are at constant risk for dangerous high or low blood-glucose levels, both of which can be life threatening.

One technological solution to address the challenges of living with T1D are continuous glucose monitoring (CGM) systems, FDA-approved medical devices that allow people to measure and display real-time blood glucose readings and track fluctuations in their glucose levels. CGM devices have given people access to increasingly accurate BG data; and yet, until recently, have had several design limitations in terms of daily diabetes management. Companies like Medtronic and Dexcom, which produce commercially available CGM systems, have kept the data generated through the continuous readings of their devices proprietary. Real-time BG data, for instance, can typically only be displayed on a designated receiver supplied by the device manufacturer; furthermore, the general usefulness of the display is hampered by the receiver having to remain within 20 feet of the CGM sensor (which is embedded in the arm of the person with T1D). New technological solutions to such limitations, such as remote monitoring of diabetes data via mobile phones, have only recently begun to enter the marketplace in 2015 (e.g. Dexcom Share and the Dexcom G5) with commercial solutions.

In 2013, a time when no commercial solutions were available, a small group of concerned T1D parents and adults with T1D formed online around the shared goal of intervening in the highly regulated and closed system of T1D data management to better manage patient care. Their efforts became an open source project to “put their Dexcom CGM in the cloud” and enable the remote monitoring of CGM data through mobile devices like smartphones or Pebble watches. Nightscout, as this project is now known, describes itself an “educational source code for monitoring estimated glucose values from a Dexcom G4 Receiver” (http://www.nightscout.info/). Over the last three years, Nightscout has quickly gained a large number of devoted users who have created an assemblage of digital tools, social support, and organizational resources around this T1D technology. Nightscout currently has several dedicated websites, instructional YouTube videos, an associated 501(c) 3 foundation, memes, Github repository, community certificates and awards, diabetes conference presentations, “install parties,” and a growing Facebook group called “CGM in the Cloud.”

Nightscout as a Project and a Community

This paper draws on findings from an ongoing ethnographic study of type 1 diabetes technology. To date, we have conducted 20 semi-structured interviews...
with members of the Nightscout community and other related DIY/making diabetes communities such as #OpenAPS (an open source artificial pancreas project). We have conducted over 12 months of ethnographic observations of Nightscout presentations at diabetes conferences and technology workshops, along with informal planning conversations held by core developers and foundation board members. Our work also incorporates an analysis of various T1D websites, personal T1D blogs, code repositories, technical documentation and social media accounts, and draws on a survey of CGM in the Cloud Facebook Nightscout users completed by 727 respondents.

Rig and Data Display
While several versions of code and configurations of devices exist (i.e. xDrip, a DIY/open source hardware and a software application connected to Nightscout), most participants in our study used the "community build" for monitoring blood sugars. This Nightscout system consists of a "rig" (the combination of a smartphone + Dexcom CGM receiver). An Android application transfers data from the CGMS to the cloud. A web application displays the BG values stored by the CGMS, and these values can then be displayed on a mobile or wearable device, such as a smart watch for displaying data.

"DIY Medical People"
Early in its development, Nightscout’s design was primarily led by the efforts of small, cohesive group of self-described “father engineers” and “diabetes dads” who networked on Twitter and shared code through email. Over the last three years, however, Nightscout has grown into a diverse community of users from adults living with T1D who have programming expertise to nontechnical parents desperately trying to sleep through the night without getting up to check on their child’s blood sugar. A common trait that unified many of the Nightscout users we interviewed was their personal commitment to diabetes innovation: One participant described Nightscout as, “a bunch of do-it-yourself medical people.” Given a wide range of perspectives on managing diabetes, however, a number of organizational sub-communities have emerged to help support the technological development of Nightscout and meet different social needs.

Currently, a small group of approximately 10-15 core developers (led by one longstanding and highly active member) work on releasing new Nightscout software versions, fixing bugs, and designing new applications. The developers are all volunteers, taking on projects as time and interest allow. Many of Nightscout’s current features were originally developed as personal tools by developers to meet their own idiosyncratic diabetes management and treatment needs (e.g. louder alarms, push notifications, predictive algorithms).

As of January 2016 the CGM in the Cloud group has more than 15,000+ members and its own dedicated 24/7 technical support team. Activities on the group have also expanded past questions about setup and installation of rigs to include sharing patient expertise on managing insulin corrections during a child’s growth spurt, showcasing DIY making projects like designing rigs to stay on small children or connecting Hue lights to Nightscout alarms, and selling or giving away medical equipment like old pumps that are used by members for testing new DIY software projects. As the community grows, new tools, hacks, advice and applications are being created and shared.
Questions and Considerations for HCI

Workshop areas of interest include: In what ways do the DIY/making/hacking practices found in emerging open data/open source health communities like Nightscout promote individual physical and emotional wellbeing as well as broader health activist goals? What types of work and labor are involved in the development and use of DIY health and self-care technologies, and how might they be supported?

Emerging cultures of DIY technology production

There has been a growing interest in DIY making and hacking cultures within HCI. Prior literature has investigated DIY making as site engagement with diverse materials [9], including electronics [1], and in terms of lay expertise and open sharing communities [10,11]. As DIY making and hacking continue to intervene in broader industrial, economic and social processes [5], we are interested in how DIY health and wellbeing draws attention to “making” as a form of labor that extends beyond current narratives of a hobbyist engagement with innovative materials or industrial entrepreneurship.

Our research suggests that this patient-driven approach to “making” is grounded instead in the daily frustrations of people who live with chronic illness and the anxious, sleepless nights of parents, and loved ones who watch over them. It is a type of care work driven by necessity: both a person’s malfunctioning pancreas and a parent’s desire to protect their child from harm. Moreover, it is a form of collaborative making centered explicitly around real time data decisions involved in everyday care to advocate for broader systemic changes in medical care. We are interested in learning about alternative forms of DIY/making found in other patient communities.

Expanding the role of patient expertise in healthcare

DIY health and wellbeing offers HCI researchers insight into current challenges around personal data tracking [3] and self-care management of chronic illness [7], as well as direction in the emerging design spaces of patient-based medicine [6] and “wellth” [2]. Nightscout, for example, is as much about individual-level action in response to health data as it is about a grassroots movement among patients and caregivers to challenge institutional arrangements in the medical field, i.e. who gets to provide and decide what counts as care; who gets to design health care.

Can and should DIY/making activities around health and wellness be viewed as examples of an “activist health technology” [8]? Groups like Nightscout may offer the field of HCI new ways of thinking about the role of personal data as an agent for social change for participants in a patient-driven medicine; alternatively, DIY health initiatives may unfairly place the burden of care on the patient. We believe future HCI research needs to critically examine DIY health narratives in relation to patient groups with limited resources and technical expertise. What might DIY health as a care model—and form of activism—offer socio-economically disadvantaged communities struggling with significant health disparities [4]? We are interested in using the workshop to identify unintended consequences around DIY health & wellbeing HCI-related research.

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