Chronologic: Tracking Stories of Illness in Chronic Care
Jonathan Cook

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Committee:
Tad Hirsch
Karen Cheng
Axel Roesler

Program Authorized to Offer Degree:
School of Art, Department of Design
University of Washington

Abstract

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Jonathan Cook

Chair of the Supervisory Committee:
Tad Hirsch
School of Art, Department of Design

New consumer technologies give patients access to a wide range of health data outside the needed expertise of doctors. Self-tracking can help chronic illness patients take more control over their health, but the participation of doctors is important for interpreting tracked data accurately. Chronologic is a platform for patients and clinicians to track and manage chronic illness together, which illustrates how new patient-centered technologies can be responsibly utilized in clinical care.
chronologic
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Jonathan Cook
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PREFACE

My aim in attending graduate school at the University of Washington has been to gain experience using interaction design to respond to complex problems in society. The medical industry is one area where the role of design has been growing in recent years. As new technologies emerge and as the industry deals with pressure to become more efficient, there is potential for designers to help positively shape those shifts. Medicine is also a convenient area to work in when studying design at a large research university like the University of Washington. The connections I’ve made with other professors and students in the Medical School, Communications, and HCDE have helped shape Chronologic, and I am grateful for the support I received.

This project began as a response to the current hype surrounding health and wellness tracking technology. Since I started researching this past fall, that interest has only increased with large corporations like Apple and Samsung bringing new products and software into the market. As someone who has experienced family members’ frustration with the current medical system’s inability to improve chronic illness, I’m among those excited by the potential of new tracking technologies to help patients gain insight into their health. Autoimmune diseases run in my family and are a group of conditions with limited treatment options. There is a hope that health tracking can lead to chronic illness patients better understanding and managing their disease. There is much work left to be done, though, before tracked patient health data can be used in clinical care. This project proposes one way to help close that gap.
ABSTRACT

New consumer technologies give patients access to a wide range of health data outside the needed expertise of doctors. Self-tracking can help chronic illness patients take more control over their health, but the participation of doctors is important for interpreting tracked data accurately. Chronologic is a platform for patients and clinicians to track and manage chronic illness together, which illustrates how new patient-centered technologies can be responsibly utilized in clinical care.

SIGNIFICANCE

A recent Pew research study shows that patients with chronic illnesses are more likely to track symptoms, and to find health insights from tracking (Fox & Duggan). New consumer technologies today give them access to a wide range of health data outside the needed expertise of doctors. This project explores ways to bring new health tracking technologies into clinical care. Making self-tracking methods accessible to people living with chronic illness can help them be more aware of their illness and take more control over their health in daily life. Finding ways to bridge the gap between the needs and expectations of patients and doctors will better pair providers and patients in the care of chronic illness. Chronologic, as a concept platform, proposes one way for patients and clinicians to track and manage chronic illness together.
BACKGROUND

Chronic illness is a major problem in the U.S., accounting for 75% of annual health care costs and seven out of ten deaths each year (CDC). Chronic illness care differs from acute care because it involves helping patients manage their symptoms (instead of recovering), and changes the traditional role of doctors from experts to advisors—and patients from recipients of care to active participants and co-investigators (Watt). P. F. Brennan and J. B. Starren articulate how these traditional roles are defined in Bioinformatics:

“Patients have been socialized to assume a passive, dependent role in health care, presenting themselves for diagnosis and treatment with little planning. At the same time, clinicians have enjoyed the privilege of control, holding fast to the possession of expert knowledge and therefore direction to patients”

- P. F. Brennan and J. B. Starren

Like chronic illness care, new technologies that provide patients access to health information also adjust traditional patient and doctor roles to be more collaborative. New models of care driven by access to health information outside the clinic may be beneficial to patients with chronic illnesses because of the important role of self-care in managing chronic conditions. They will require, though, a different approach from doctors involving more time to assist patients with the interpretation of self-tracked information in light of their specific situations. This interpretation will be most effective if it relates to the patient’s social and environmental well-being, as well as their physiological health (Shortliffe & Cimino). These new developments place the doctor as an advisor to the patient’s self-care and active investigation of health. One of doctors’ new challenges in this model is to be experts at recommending reliable resources for self-investigation, and to be adept at guiding comprehension and co-interpretation of data with patients (Swan). Platforms that are designed to present self-tracked data with this new model in mind will be the most successful at enabling collaborative decision making between patients and doctors.

A number of the barriers to integrating health tracking into clinical practice are outside the scope of this research, including the security of tracked data, the reliability and accuracy of biometric sensors, and organizational models that compensate clinicians for remotely advising patients. One difficulty that is addressed in this research is how doctors and patients approach health data with different assumptions regarding what information is important to manage illness. Fiore-Silvast and Neff and call these points of interpretation “data valences,” and outline six that illustrate the tensions emerging from new medical technologies. The valences they describe involve the perceived actionability, accuracy, and transparency of tracked data (Fiore-Silvast & Neff). They advise that health tracking tools be designed to promote better communication and collaboration between patientes and doctors to help bridge their different needs and values. Presenting patient stories alongside biometric sensing data may be one way to visualize a broader picture of health that both groups can align to.
“In our case study, patients and doctors value and expect different things of the same data.”

“We found the gaps in communication about data were particularly stark across the communities of technology designers, ‘e-health’ providers and advocates, and users of health and wellness data.”

- Brittany Fiore-Silvast & Gina Neff

Research conducted by Brian Smith et al. provides one example of how biometric and self-tracking data can be used to promote conversation and reflection in the management of diabetes. In “Integrating glucometers and digital photography...” the researchers analyzed how patients’ pictures of food were used alongside continuous glucose tracking measurements with a doctor. The study showed that using photography with quantitative measurements was useful to stimulate memory of past actions, to provide context to biometric measurements, and to promote storytelling and conversation with doctors. They found that quantitative data alone was not sufficient to help patients and clinician’s manage illness, but required additional contextual and qualitative data before it could provide insight. The authors articulate that,

“...glucometers provide data about how a person is doing, but they do not record activities that could explain why glucose levels are low, elevated, or normal.”

“Despite their value as tools to record and present physiological data, they lack the ability to capture behaviors that cause fluctuations in blood glucose levels, activities that ultimately need to be understood and managed in order to maintain good health.”

- Brian Smith, et al.

Pairing glucose measurements with photography allowed clinicians more insight into the daily routines of patients, and thus, information that they could use to help patients manage their condition. The act of taking a photo was also shown to promote the patients’ “reflection-in-action,” helping them be more aware of how their actions affected their disease management.

Improving doctor-patient communication in chronic illness care, generally, has been shown to also improve many patient health outcomes (Ong et al.). Yun et al., in a study of pediatric asthma patients, found that collecting health status information from patients via SMS between visits provided doctors with additional useful information that added to conversation during check-ups (Yun et al.). These SMS responses from patients were communicated to physicians through a web-based visualization tool, illustrating one example of how doctor-patient communication can be augmented by mobile technologies, and how that tracked information can be communicated back to a doctor.
Some are already researching new ways of incorporating health tracking into clinical care with positive results. Patel et al. in “Probing the benefits of real-time tracking during cancer care” show that tracking health data can help cancer patients remember, communicate, and legitimize their symptoms with a doctor (Patel et al.).

“Yet, patients have difficulty communicating the full extent of their symptoms to clinicians, as they manage symptoms away from the clinic, in between chemotherapy infusions, surgeries, radiation treatments, and follow-up appointments.”

- Rupa Patel et al.

In order to research health tracking in cancer care, the authors created and tested an application which allowed patients to track when their symptoms occurred and how intense they were. Engagement with the application was high and helped support communication with clinicians by allowing patients to reference a record of their symptoms. The researchers also found that some patients took psychosocial comfort in the tracking — having to reflect on their illness knowing that their health was being documented to communicate to others. The authors conclude the paper with five considerations for future health tracking technologies, including allowing customizable symptoms, giving guidance to patients on what to initially track, and promoting communication with clinicians.

Despite the promise of new patient-centered technology to improve chronic illness treatment, care should be taken in how these new technologies become integrated into clinical and insurance systems. Researchers have shown that the problem of chronic illness in the U.S. is very much tied to larger social and economic inequalities, creating what’s known as a “social gradient of health” that is consistent across income levels. Requiring or incentivizing health tracking as a part of wellness plans seems plausible, but may make health insurance systems significantly more inequitable (Schmidt et al.). These issues point towards the need for collaborative systems of care that allow health tracking and the use of new technologies to remain patient-initiated, driven and managed, so that patients can be in control of their health data by choosing what they feel comfortable tracking and sharing.
Outside the medical field, researchers in Human Computer Interaction have looked at how self-tracking works in practice. Li, Dey, and Forlizzi provide a number of useful considerations for designing general tracking platforms in “A Stage-Based Model of Personal Informatics Systems.” After conducting research with people who track personal information in Quantified Self groups, the authors constructed a model of self tracking (Figure 1) to help communicate the specific difficulties encountered in each stage of the process (Li et al.). The five stages they present are “preparation, collection, integration, reflection, and action” and the authors make a useful distinction between the “user-driven” and “systems-driven” tracking that can occur in each stage. The authors advise a balance between automating tracking and allowing customization in order to ease the burden on users while allowing some control. User-driven or manual tracking, while more time consuming, has been shown to promote reflection. The authors suggest designing whole tracking systems, as opposed to specific pieces of a platform, in order to avoid early difficulties affecting later stages of tracking. Though not specifically medically related, their research provides valuable insights into how technology can be designed to best support self-tracking that is both convenient and that produces actionable insights. Their “Stage-based Model...” also presents a research-based framework that designers of new tracking technology can use to help structure new applications.

Figure 1
“A Stage-Based Model of Personal Informatics” Li, I, A Dey, and J Forlizzi
RELATED WORK

Most existing health tracking technology is designed with the needs of either patients (often as consumers) or clinicians in mind, rather than bringing the two groups together in order to promote the collaboration needed to manage chronic illness. Using a 3x3 matrix with axis for data type (quantitative and qualitative) and audience (patients and clinicians), I’ve reviewed the following areas of health tracking technology: consumer health and fitness, prevention plans and shared electronic health records, medical surveillance technologies and EMRs, Quantified Self, medical social media networks, and patient diaries (Figure 2). The center square of the matrix represents one of the goals of Chronologic — to design a platform for both audiences that combines quantitative tracking data with qualitative contextual information. Lastly, in order to explore different methods of portraying patient data over time, I compiled a selection of related visualization examples to reference (Figure 3). (See the appendix for a list of related applications in each area).

There are a few organizations that are already, or will soon be working in this middle space between patients and doctors. One interesting social media example is Crohnology, which is a network for IBD (inflammatory bowel disease) patients to share treatment advice based on their tracked symptoms. Though their website was created with patients in mind, the company is currently conducting research on how its symptom tracking system can be integrated into clinical care. Another promising example is C3N (the Chronic Collaborative Care Network), a care system for children with IBD that was designed to include health tracking and information sharing between patients. The C3N network shows promise in many areas involving how technology can be used in chronic illness care, in part, because researchers were able to create it as a wholly new system of care within The Cincinnati Children’s Hospital. Notably, they’ve included designers in this work from the beginning. Even though the network has only released a few examples of applications being used with patients, the C3N system appears to be paving a new way forward in chronic illness care.

“To make it simple, let’s break up C3N into three parts 1) Social – frequent and easy interactions between participants, like patients, clinicians, and researchers; 2) Technical – information systems, for the multitude of data; and 3) Scientific – an arena to try and test new ideas.”

- C3N Website
Figure 2
An Overview of Health Tracking Technology
Figure 3
Related visualization examples
(See appendix for sources)
DESIGN QUESTIONS

One important designer currently working to improve chronic illness care is Katie McCurdy. As both a UX designer and a chronic illness patient, her insights are based on firsthand experience seeing the drawbacks of the current medical system. Below, she describes a tool that might help patients communicate a symptom history to physicians (McCurdy):

“The question remains – can we create a tool expressly for visualizing personal medical histories, one that accounts for both ‘hard’ data points like medication dosages and procedures performed, along with ‘soft’ data points like how the patient felt (physically and mentally emotionally)? I think this is a design problem worth pursuing.”

– Katie McCurdy

Building off the above quote and my previous research, I began the design exploration of Chronologic with two key questions in mind related to integrating patient tracking into clinical care:

1. **How can individually tracked data be used by doctors and patients to collaboratively manage chronic illness?**

2. **How can the design and presentation of qualitative and quantitative personal data best communicate a patient’s story of health?**

In order to answer these questions, I interviewed doctors and patients and created a number of design artifacts to test and guide my concepts. The following section documents each of these methods in the process of designing Chronologic.
A COLLABORATIVE MODEL OF CHRONIC ILLNESS TRACKING

Though Li, Dey, and Forlizzi’s “Stage-based model of personal informatics” provides a useful structure to think about designing tracking platforms, it could be adjusted to be better relate to the complexities of chronic illness care. Based on my research outlining the current gaps between patient tracking and clinical care, I designed “A Collaborative Model of Chronic Illness Tracking” (Figure 5). Instead of a linear and individual timeline, this model cycles between clinical visits when the doctor and patient make sense of tracked data together and then plan the next steps of care. Affinity diagramming my research using themes for patient and doctor experience, chronic illness care, and health tracking helped to organize my findings into the new model (Figure 4).

This new model provided a structure for the design of Chronologic and helped me understand how patient health tracking could transition into a clinical visit when the patient and doctor co-interpret data together. The model begins with both parties collaboratively identifying the best variables to track. During the tracking phase, the patient reflects and annotates their symptoms with more detail. Before a visit, the patient flags key dates and then shares a report with their doctor. This curation process helps to manage the amount of data to review by focusing doctors’ attention on the patient’s experience. During a visit, the doctor and patient review a symptom history together, and then re-assess the patient’s tracking and care plan—before the cycle continues with the new insights they gained.

Figure 4
Affinity Diagram of Health Tracking & Chronic Illness Research
Figure 5
A Collaborative Model of Chronic Illness Tracking
SYMPTOM JOURNALS

In order to test how easy and useful it would be for patients to self-track symptom severity and possible health factors, I designed and printed a number of small symptom journals (Figure 6). As opposed to a mobile or paper prototype, the printed journals allowed me a simple way to gather data from patients over a period of time without having to be present with them. Four friends and family members with different chronic conditions used the journals over two weeks. In order to structure the tracking to work like it would with a mobile application, daily notifications were set up on each person’s phone to remind them to write their symptoms down either once or twice a day. After the two weeks I met with each patient to discuss their thoughts on the tracking process and to present different visualizations of their tracked data (Figure 7).

These interviews confirmed that the tracking structure I’d designed was quick and easy to use, and provided insights that helped me refine the timeline graph design on the tablet application. One of those insights was that displaying a history of symptom severity helped the patients recall specific stories about their health. Though the graphs that summarize health factors (lower-right of Figure 7) didn’t fit within the storyline that influenced the final version of Chronologic, two responded positively to way they aggregated larger findings from their data. One challenge with this aggregation of health data is to not make substantial claims before the patient has reviewed the data with their doctor. Future research would be helpful to navigate how aggregating patterns from tracked data could be useful to patients without taking the place of doctors’ expertise. Three of the four patients who took part tracked consistently throughout the two weeks, and all thought that the paper-based tracking was beneficial in some way.
Figure 6
Symptom journal based on the Chronologic tracking framework

Figure 7
Visualization examples of tracked data from the symptom journal research
PATIENT AND DOCTOR INTERVIEWS

I interviewed four patients and five doctors to get feedback on the Chronologic idea and my specific interface concepts. Two of the five interviews with doctors were part of a research study conducted by a HCDE PhD student at the University of Washington. The two doctors in that study worked in Exercise Science and General Practice, while the other three I interviewed were from Oncology (two), and Gastroenterology (one). During the interviews, doctors were asked about treating chronic illness patients and their experience with patient tracked data (see the appendix for a list of sample questions). I also presented doctors with multiple variations of the Chronologic tablet application design in order to test the presentation of patient information and the most useful information to include. Though ideally I would have interviewed more doctors, their insights had a large impact on the Chronologic tablet application design. All but one doctor interviewed thought the Chronologic idea would be useful to them in practice.

Three of the four patients I interviewed were family members who deal with at least one chronic autoimmune condition. One family member was interviewed multiple times to get feedback on different iterations of the mobile and tablet design. Her experience managing the complex autoimmune disease Myasthenia Gravis influenced much of this project. The fourth patient, also a Myasthenia Gravis patient, was recruited from a publicly listed, local support group for the disease. This study received an IRB exemption from the University of Washington to conduct informal interviews with patients. During the interviews patients were asked about their use of technology to track or manage their disease, about the positive and negative experiences they’d had communicating with physicians, and about their opinion and understanding of the Chronologic designs. Some of the insights gained from speaking with patients involve the importance of including medication history alongside symptoms and the inclusion of a meeting agenda with the shared report. The following section outlines three key themes from the interviews with doctors and patients in a more detailed description of the Chronologic platform.
Figure 8
Presenting Chronologic mobile application designs for feedback.
THE CHRONOLOGIC PLATFORM

Chronologic is a platform comprised of a mobile and tablet application that allow a chronic illness patient to track and share a history of their health (Figure 9), and then view that information with a doctor (Figure 10). The platform is described in more detail on the following pages as it relates to three key themes from my research and interviews.

Figure 9
Chronologic mobile application showing a two step tracking process (first and second screens), and a prompt to annotate a symptom (third screen).
1. Meeting Agenda

A patient’s meeting agenda that was shared with a doctor can be referenced during a clinical visit.

2. Health History

The doctor and patient view a timeline of symptom severity and overlay possible causes the patient tracked. They expand details from each day and compare similar dates to find patterns.

3. Visit Summary

At the end of a meeting, the doctor updates details of the patient’s care and tracking plan, and records a note for the patient to document why a decision was made.

Figure 10

Chronologic tablet application with scenario details for each section.
THEME 1: AUGMENT THE PATIENT’S MEMORY

All of the patients I interviewed spoke about how Chronologic would be helpful to augment their memory during appointments. They mentioned often having to wait two to six months between appointments, making it difficult to remember details of their health. This finding is consistent with the research from Patel et al., which was based on a tracking application that created a line graph of symptom severity. In addition to tracking symptom severity through daily notifications to view as a line graph, Chronologic is designed to augment patient memory in three specific ways:

**Structured Reflection**

During a symptom flare patients may not feel well enough to write a note explaining their illness. Chronologic waits until symptoms have subsided to prompt the patient to reflect and write a note on why they may have been feeling bad (Figures 9 and 11). This note appears as an annotation mark on the symptom history timeline that the patient and doctor view together (Figure 10). The mark can be expanded to show details from each day in order to guide their conversation to the patient’s written experience.

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**Figure 11**

Scenes from the Chronologic video showing a patient tracking a severe symptom, and then reflecting on it later.
The Patient’s Agenda

In addition to forgetting details about how they felt, patients also remarked that they often forget what questions to ask doctors during clinical visits. Because visits can be as short as 5-10 minutes, the patients I spoke with commented on the difficulty of always leaving appointments with the information they need. When sharing a report with a doctor using Chronologic, the patient is asked to write a brief meeting agenda (Figure 12). The agenda can then be reviewed by doctors before appointments so they can best prepare to manage the patient’s concerns (Figure 10).

Figure 12
Scene from the video showing a patient writing a meeting agenda for their doctor.
**Documented Decisions**

Consistent with forgetting questions during brief appointments, two patients I spoke with also sometimes left visits with an incomplete idea of why certain decisions were made with their doctor. Though many hospital systems now provide printed reports after visits to help this, it would make sense for these notes to be included in a platform like Chronologic to view later. These notes would also document why decisions were made throughout a patient’s history of care. The third area of the tablet application includes functionality to document why any changes were made, as well as adjust a patient’s care and tracking plan (Figure 13).

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**Figure 13**

Third section of the Chronologic tablet application where meeting notes can be added.
THEME 2: EFFICIENTLY COMMUNICATE INFORMATION TO DOCTORS

Though all but one of the doctors I spoke with thought the Chronologic idea could be useful to them in practice, their biggest concern was the increasingly limited time they have to review patient information. Two doctors told me specifically that they often have five minutes or less to review patient data before appointments. This underlines the need for Chronologic to present both the right information, and for that information to be presented clearly and efficiently. Two design features of the platform help accomplish this.

3-part structure
One doctor was particularly overwhelmed with an early version of the Chronologic tablet application design because it included all relevant data on one screen (see Figure A3 in appendix). After, she showed me the left navigation structure of the electronic medical record system she was most familiar with. In order to both mimic the navigation of the EMR that doctors are familiar with and to better separate patient information, the Chronologic tablet application includes three sections that follow the sequence of a typical clinical appointment (Figure 10). With this design change, the doctor and patient can easily transition from viewing a meeting agenda to exploring a symptom history, and eventually to documenting any care plan changes.

Curated Data
One problem with any integration of patient tracking into clinical practice is that the amount of data generated is often too big for a doctor to review. As one doctor put it, he is interested in investigating the “peaks and valleys” of the data — or the changes in the patient’s health that occurred. By structuring patients’ annotation of their tracked data when symptoms change, it can help to focus the doctor’s attention on the snapshots of tracking that matter most. Presenting a line graph summary of data, while allowing more detailed, daily information to be revealed if needed, also helps to manage the amount of data initially presented to the patient and doctor (Figure 14).
Figure 14
Health history timeline on the tablet application showing an annotation from one day, and the patient’s medication adherence overlaid below.
THEME 3: PROMOTE STORYTELLING & CONVERSATION

The third key theme that emerged from my research is the important role that qualitative patient data plays during clinical visits and in the treatment of chronic illness. One doctor explained that he always asks his patients what they think is affecting their symptoms. He doesn’t do this because they necessarily know the cause, but in order to help him gauge how he can best help the patient cope with and manage their disease. In his experience with chronic illness, he often already has the quantitative data he needs. Understanding the qualitative aspects of the patient’s health is more difficult, and takes time during clinical meetings to accomplish. Though one goal of Chronologic is to combine qualitative and quantitative health tracking, the patient’s story is specifically emphasized through the interactive health history timeline.

A Rich Symptom History

Presenting visualizations of the data from the symptom journals made it clear that a timeline of symptom severity helped patients recall stories about their recent health. Adding written patient annotations to this timeline further focuses the graph on the patient’s lived experience (Figure 13). Photos could also be included in the annotation, if relevant to the patient’s illness, to promote conversation. Any automatically tracked data can be overlain below the symptom graph to look for correlations with the patient’s symptoms and experiences.

Doctors’ mistrust of patients emerged as an issue in some of my interviews and in Patel et al.’s research, which showed how sharing tracked information with doctors can help legitimize the patient’s past experience. Presenting qualitative health tracking in a structured graphical format helps this issue by assuring doctors of patients’ accurate recollection. Including both quantitative symptom tracking data and written patient annotation is key to navigating this space between communicating a patient’s medical symptom history along with their lived experience to doctors.
VIDEO PROTOTYPE

In order to best communicate how Chronologic would help patients and doctors manage illness over time, I created a video illustrating one possible storyline of the platform’s use. In order to make sure the video was realistic, I met multiple times with the previously mentioned family member to get her feedback on different scenario ideas. The story in the video is a result of those conversations about her experience managing a complex autoimmune disease. The video shows a patient dealing with worsening symptoms that she thinks might be the result of a food allergy. After presenting her health tracking and agenda to a doctor, they decide that her medication is probably at fault, and adjust her care plan accordingly.

Figure 15
Storyboards created for the Chronologic video
NEXT STEPS

A few issues would need to be resolved before the Chronologic concept would be ready to move forward towards development. First, the issue of how the platform would be integrated into current EMR systems would need to be addressed. The social media and health tracking application Crohnology is currently being tested within a medical system, showing that it is possible to integrate outside applications into clinical practice. Further research would need to be done to know how this was accomplished. If integration with current health systems isn’t possible in the short term, it may be useful to develop Chronologic as a patient facing application that could be brought to doctors. Though not ideal, it could provide a positive example to doctors and influence future adoption by health systems. Eventually, the effects of using Chronologic in clinical care would need to be tested, requiring stronger collaboration with doctors and a specific patient population. Though the qualitative tracking aspects of Chronologic could relate to all chronic illnesses, some aspects of the platform would likely have to be adjusted to fit different patient populations.

CONCLUSION

Ubiquitous computing technology like smart phones and biometric sensors give patients powerful new tools to manage their health by providing day-to-day feedback. The Chronologic concept was designed to illustrate how this health tracking can be responsibly integrated into chronic illness care in collaboration with clinicians. The speed at which patient tracking technology is being developed and adopted necessitates that researchers and doctors develop best practices for how this data should be used in the clinic. Melanie Swan in “Emerging Patient-Driven Health Care Models” articulates the importance of doctors partnering with patients to use this new technology:

“Science, technology and business advancements could change health care so rapidly that many physicians, even those currently in medical school, may not be able to be fully prepared for the shift to genomic-based and patient-driven medicine without becoming actively involved themselves”

- Melanie Swan

Providing bridge platforms like Chronologic for these new applications of technology to be used in collaboration with the medical expertise of doctors is key to their success in assisting patients’ self-management. These bridges will require strong ties between doctors, patients, and designers—and an acknowledgement of how the traditional roles of doctors and patients change in chronic care.
REFLECTION

One of the key things I learned while working on this project over the past nine months is the importance of collaboration when working in a specialized field. Though the feedback from doctors I received was valuable and shaped the design of Chronologic, ideally a much stronger connection with clinicians would be needed for a medical project like this to succeed. Considering doctor’s time constraints to advise outside work, they would likely need to have some ownership in a project like this as part of their own research. Ideally such a research project would have very strong participation from patients as well, so that the project could evolve with feedback from both parties.

One thing I might have done to improve my overall design process would have been to create specific scenarios to show possible uses of Chronologic earlier. At times, I may have spent too much of my focus on the details of the interface, without first having a clear idea of how each feature might be used. The tracking model I created early in the process was very helpful to guide the structure of the application, but it was creating the video that made me focus on a more grounded storyline to guide the final Chronologic designs. Focusing on multiple, specific scenarios earlier would have helped constrain the amount of interface design work needed to communicate the Chronologic idea.

I can’t help but feel like I accomplished only a small piece of a much larger project. This was, in many ways, inevitable considering the complexity involved in trying to rethink current models of clinical care. Because Chronologic is a concept project, I have to acknowledge that would be much more work to be done it could survive the bureaucracy of the current medical system. The positive responses I received from patients and doctors, and the inspiring work done by organizations like C3N, however, make me optimistic that such a platform can, and will eventually be implemented.
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41 Related Work: Consumer Health & Fitness Tracking
42 Related Work: Electronic Health Records
43 Related Work: Wellness Plans
44 Related Work: Medical Social Media Networks
45 Related Work: Quantified Self
46 Related Work: Collaborative Decision Making
RELATED VISUALIZATION EXAMPLE SOURCES

*left-right, top-bottom*

memo Application
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http://feltron.com/ar10_01.html

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WNYC Vertical Timeline

Overall Strength of MLB Teams
http://www.flipflopflyin.com/flipflopflyball/info-overallstrength.html

Feltron 2012 annual report
http://feltron.com/ar12_04.html

GE Powering the Kitchen
http://fathom.info/kitchen

The Patient Record Design Challenge
http://healthdesignchallenge.com

Fitbark Application
SAMPLE QUESTIONS FOR DOCTOR INTERVIEWS

How long do you usually have to meet with chronic illness patients?

Have you had patients who have brought tracked information to an appointment?

What is useful or unhelpful about patient-tracked health information?

What information do you hope patients will bring to an appointment?

What patient information is useful in helping them manage their illness?

What patient information isn’t helpful?

SAMPLE QUESTIONS FOR PATIENT INTERVIEWS

What’s your experience with tracking your health or symptoms?
What tools do you use?

Have you ever brought self-tracked information to your doctor?

What does a normal doctor visit look like? What do you discuss?

Is there anything frustrating about communicating with your doctor?

When has communicating with your doctor been easy?

What sort of information is your doctor looking to hear from you when you meet with them?

What information would help you manage your condition?

What information would help you better communicate with your doctor?
Figure A1
Example of symptom diary setup and daily entry pages.
Appendix

Figure A2
Platform map illustrating how the mobile and tablet Chronologic applications would work together.
Figure A3
Previous version of tablet application design with all information on one screen.
CONSUMER HEALTH & FITNESS TRACKING

Basis Band
Like many other consumer technologies, Basis Band allows people to track and set goals for their fitness, sleep patterns, and heartrate through a wearable device that connects to a mobile interface.

Other related applications/devices include: Nike Fuel Band, FitBit Flex, Withings Pulse, and Polar activity and heartrate watches.

BodyMedia Fit
One of the first consumer device/applications in health and wellness, BodyMedia is an FDA approved device that has been used for medical research and clinical use.

ARGUS - Motion and Fitness Tracker
Fitness tracking application that uses the iPhone 5S’ new M7 motion co processor to track activity and sleep. It also lets users sync other devices as well as manually track many different health variables.
Bodywise Health & Fitness Application
Simple, bright interface for tracking a handful of health and fitness measurements. The application is easy to use, but doesn’t allow much customization or a way to output data.

TicTrac application
Platform that syncs multiple applications and devices in order to track a number of different personal data in one place.

Apple Health
Apple’s Health Application was announced in May, 2014—a few weeks before this project ended. The application in its first iteration will compile data (sleep, physical activity, heart rate, etc.) from outside tracking devices into it’s own interface of information visualizations. Apple has announced that it is currently working with both Mayo Clinic and the medical record system, EPIC, in order to devise a way to share this information with doctors. They’re also widely rumored to be releasing an ‘iWatch’ device within the year that will track biometric data.
US Gov Medical Records Design Challenge
Recent pushes to digitize medical records have spurred a number of designs that organize medical information and patient records for doctors and medical staff to interact with.

This is the winning entry from design studio Gravitytank for a US government sponsored EHR design contest.

Practice Fusion Application, by Cooper
This is a tablet-based EMR designed to give doctors a clear overview of a patient’s information, and to allow them to quickly update a patient’s record “by touch or voice.” Cooper conducted ethnographic research in order to design the application based on doctors’ workflow and information needs.
Seattle Children’s Application, by Artefact
Artefact designed this concept EHR based on research with the Seattle Children’s Hospital to accommodate different clinical staff and to be adaptable to different computer platforms.

Bosch’s Health Buddy
Physical device target towards the elderly to track health and vitals.

“Through a combination of symptom review, vital sign gathering and education/health coaching aimed at the support of positive behavior change, the Health Buddy System is able to engage patients and provide context to healthcare providers which allows them to intervene before health deterioration occurs.”

Macaw Application from Prevention Plan
Health and Fitness tracking application with card-based interface for different activities. The application was built to be used with health providers and prevention plans and links with physical devices like fitbit and bodybug.

CarePass from Aetna
Wellness application that aggregates data from different sources, and allows users to track and set goals, as well as search providers to schedule medical appointments.
**MEDICAL SOCIAL MEDIA NETWORKS**

**Crohnology**
Social network for Crohn’s disease patients to both track and share symptom and treatment data with others suffering from the disease.

**PatientsLikeMe**
Social network designed for patients to find others struggling with similar conditions to gain advice and support, and to track the effectiveness of various treatments.

The network also has tools to self-track different qualitative and quantitative variables, and to organize and output a personal health record for doctor visits.
BodyTrack/Fluxstream
Open source platform for overlaying numerous tracking apps and devices on the same interface. Visualizes photos on top of data over time.

PersonalExperiments.org
Website dedicated to providing structure and a platform for people to conduct self-tracking experiments on themselves in order to gain insights in areas like productivity and health.

“Personal Experiments will help you explore your health and wellbeing, while sharing and learning with others, complementing your work with your doctor. The decisions you make about your health are ‘everyday experiments’ that we can help you record and learn from.”

Reporter
Reporter was created by well known quantified self designer Nicholas Felton. The application prompts users at random times to track their own customizable variables, and creates visualizations based on the data.
**Katie McCurdy Health Visualizations**

Health visualizations that an autoimmune disease patient created to communicate her medical history to the many doctors she sees for her condition.

**Symple Symptom Tracking Application**

Application that allows a user to track symptoms and the factors that may influence those symptoms. The application includes functionality to record text journal entries and add two daily photos. It also includes a feature to output data to a doctor or health provider by data ranges (three months, six months, and all data).
C3N: Collaborative Chronic Care Network

“Lybba created the C3N platform to help patients track their health between appointments, visualize their health over time via clear and engaging graphics, more easily communicate with their physicians using online and mobile applications, and even choose to share their medical data with other patients and researchers.”

http://www.lybba.org/blog/
case-study-crohns-disease-c3n-lybba/

MyRA Application

Application designed to specifically track Rheumatoid Arthritis symptoms and output a summary to present to a doctor. A well-designed application that overlays information about well-being, pain, fatigue, activity, medication, and lab results.