

Heron

Investigating concepts in
personal health informatics for
individuals with chronic conditions

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March 2024

Background

The landscape of personal health today presents important challenges and opportunities.

Self-management and self-advocacy are essential for achieving positive health outcomes, particularly for individuals with chronic conditions.

Today's healthcare landscape presents unique challenges for those with chronic conditions. It can take months for an initial appointment with a specialist, requiring immediate self-management¹ and self-advocacy² while going untreated during the critical initial months of a disease's progression.

During medical appointments, patients must quickly communicate a wide range of information with their doctors, often relying on memory to recall experiences and express health goals and preferences gathered over a long span of time.

Health insurance providers make the final decision on which medications and procedures will be approved and how they will be administered, requiring continued self-advocacy for the prescribed treatments to avoid a lapse in care.

Reviewing outcomes and reacting to problems only at doctor visits would greatly limit the number of adaptive strategies³ that can be implemented and evaluated each year. Chronic conditions require regular at-home experimentation with adaptive strategies to find potentially compounding improvements. This self-management is critical for anyone navigating life with a chronic condition.

Because of these constraints, self-management and self-advocacy are essential for achieving positive health outcomes.

Individuals with chronic conditions have limited access to meaningful data needed to enable transformative self-management and self-advocacy.

To make well-informed decisions, individuals with chronic conditions need to know how their condition

responds to variables in and outside of their control. But the data that tells this story is not meaningfully accessible, if it's recorded at all.

Medical information, including bloodwork and laboratory results, x-rays, and doctor's notes, is tucked inside electronic health records which are often illegible and difficult to access. Records of movement, diet, and sleep routine can be found in health tracking apps, if used. Various notes of side effects, aches and pains, or confusing symptoms are written in journals or recorded in note taking apps.

Data collection can be cumbersome and tedious for the individual, adding to the burden of disease management. Existing data is disparate and disconnected, making it nearly impossible to recognize and understand connections to inform adaptive strategies.

Unable to access meaningful data, individuals are not well-supported in their efforts to self-manage and self-advocate.

Personal technology harbors the potential to support individuals in search of positive health outcomes with new methods of data collection and interpretation.

Today's technology landscape presents the potential for a very different story for how individuals with chronic conditions leverage data related to their personal health.

We envision a future in which such an individual can easily collect all relevant data in one place, and flexibly arrange visualizations that help discern possible answers to the questions they care most about. These visualizations give individuals an opportunity to actually "see" the data instead of relying on hunches or holding information solely in their memories. They're able to experiment with and refine their adaptive strategies quickly, forming many small iterative cycles, the benefits of which compound. They can follow along with

¹ Self-management, defined as the process by which one manages their disease(s), symptoms, treatment, and lifestyle for the individual's self-determined quality of life.

² Self-advocacy, defined as the process by which one expresses their experiences, concerns, needs, desires, and decisions to healthcare professionals, to improve one's healthcare outcomes.

³ Adaptive strategies, defined as changes made to therapeutic interventions and lifestyle.

the outcomes of changes to their prescriptions, and find correlations between possible triggers and their symptoms. They are able to make more informed decisions, and advocate to their healthcare providers with clear data. And, as people with chronic conditions often rely on one another, better outcomes for one mean better outcomes for their network.

Such a future is feasible with today's technology. But what's needed now are new constructs for data collection purpose-built to work well within the context of someone's life while navigating a chronic condition, and interfaces that are able to flexibly represent diverse data and the associations within it to answer individuals' questions.

A focus on individuals with chronic conditions maximizes the potential impact.

As elaborated in the previous sections, individuals with chronic conditions experience the challenges with today's personal health landscape with more difficulty.

These individuals know their conditions intimately, as they're often lifelong and affect every day activities. They understand aspects of their conditions that their doctors don't see, requiring clear communication to help guide their doctor's support.

These individuals are already engaging in daily adaptive strategies, big and small. This existing behavior can be supported with data that helps people more concretely, and more quickly, confirm positive health outcomes from changes to their adaptive strategies, and iterate on ineffective adaptations.

Individuals with chronic conditions dedicate a considerable portion of their time to their health with some individuals allocating up to two hours each day on activities associated with personal healthcare including treatments, medical appointments, health insurance claims, lifestyle interventions, and beyond.⁴ Given the time and cost of the many interactions with doctors, insurance providers, and pharmacists, and the mental and physical toll of the therapeutic interventions employed, there is a lot of room for little improvements to have a significant impact over the course of one's life.

Six in ten US adults are living with chronic conditions, and 90 percent of the \$4.1 trillion in annual health care expenditures⁵ are for those with chronic and mental health conditions. This problem is vast, and so is the opportunity.

We believe that with better methods of data collection and interpretation, individuals with chronic conditions will be able to make more informed decisions, engage tighter feedback loops for compounding improvements, and advocate for themselves to receive improved support from healthcare providers.

⁴ Jowsey, T., Yen, L. & W, P.M. Time spent on health related activities associated with chronic illness: a scoping literature review. BMC Public Health 12, 1044 (2012). <https://doi.org/10.1186/1471-2458-12-1044>.

⁵ About chronic diseases (2022) Centers for Disease Control and Prevention. <https://www.cdc.gov/chronicdisease/about/index.htm>.

Current landscape

Existing solutions and prior research.

Industry

Within healthcare, electronic health records (EHRs) are the primary tool for a patient to access their personal health data. Today's most advanced EHRs provide health records (test results, x-rays, so on), allow for light communication between a patient and their doctor, and facilitate administrative tasks such as billing, booking appointments, and requesting prescriptions.

Beyond one's immediate interaction with their health-care provider, there are a number of health tracking applications that typically monitor specific parameters or metrics (e.g. menstrual cycle, flights of stairs climbed, etc.). Some apps have been created to service the particular needs of individuals with chronic conditions. These often focus on adherence to prescriptions by having the user record when they are taken, sending reminders to administer the medication, and offering simple ways to refill the medications. Elimination diet tracking journals and apps let users log what they ate each day, and how their bodies reacted.

My Pain Diary⁶, created for individuals with chronic pain, employs a more tailored approach with features allowing the user to enter pain levels, record information like how many cups of coffee were consumed in a given day, track feelings of fatigue and stress, and view modest visualizations.

A more robust category with similar apps is fitness tracking. Apps like Strava⁷ provide users with a range of features including activity tracking, exercise logging, and health metric monitoring. They offer integration with wearable devices for data synchronization.

Users can analyze their data and view visualizations when working toward their health and fitness goals.

Some apps take advantage of frameworks offered by mainstream OSs: HealthKit, ResearchKit, and CareKit on iOS and related OSs⁸, and Google Fit on Android and related OSs⁹. These frameworks provide common needs for health and research apps like consent form modals and APIs for sharing data. Some apps that use these frameworks include Autism & Beyond, Mole Mapper, and EpiWatch.

Academia

Personal health informatics is a growing field of study at universities globally. Personal health libraries (PHLs) have been explored in prior research as an answer to the rigid and impersonal nature of EHRs. PHLs are meant to integrate patient health data, combined with universally known health data into one secure location, giving the individual more information for informed decisions.

HemPHL¹⁰ is an mHealth (mobile health) project in collaboration with the University of Tennessee and the Hemophilia Federation of America. It collects population-level data as well as personal data from activity trackers and electronic subscription and browsing behavior to help individuals monitor hemophilia and also make recommendations about health behaviors.

Researchers from the University of Tennessee have focused on PHLs as a resource for individuals with diabetes.¹¹ Their focus is on exploring how an app that provides tailored push notifications to users can be leveraged to change behaviors.

⁶ My Pain Diary & Symptom Tracker - Mobile apps. <http://mypaindiary.com/>.

⁷ Strava | Running, Cycling & Hiking App - Train, Track & Share. <https://www.strava.com/>.

⁸ ResearchKit and CareKit - Apple. <https://www.apple.com/lae/researchkit/>; Overview - ResearchKit & CareKit. <https://www.researchandcare.org/>; HealthKit | Apple Developer Documentation. <https://developer.apple.com/documentation/healthkit>

⁹ Google Fit | Google for Developers. <https://developers.google.com/fit>.

¹⁰ Olusanya, O.A. et al. (2021) 'HEMPHL: A Personal Health Library and MHealth recommender to promote Self-Management of Hemophilia,' in Studies in health technology and informatics. <https://doi.org/10.3233/shti210231>.

¹¹ Ammar, N. et al. (2021) 'Using a Personal Health Library-Enabled MHealth Recommender System for Self-Management of Diabetes among Underserved Populations: use case for knowledge graphs and linked data,' JMIR Formative Research, 5(3), p. e24738. <https://doi.org/10.2196/24738>.

SEICHE Center for Health and Justice at Yale University has been working on Personal Health Libraries for Formerly Incarcerated Individuals (PerHL).¹² The focus on this research is improving the health of formerly incarcerated individuals through a mobile app structure that can be used to collect personal health data and localized information about community health resources.

Ad-hoc practices

Individuals with chronic conditions currently record health information in a variety of ways, relying on EHRs, health tracking apps, and other technologies already identified. However, their record-keeping isn't limited to these tools, as they take notes on their conditions and adaptive strategies using journals to record daily symptoms, medication intake, dietary choices, exercise routines, and any notable events related to their condition. Additionally, joining support groups, either in person or online, can provide a sense of community and a platform for individuals to share experiences, tips, and insights about managing their conditions.

Gaps

Existing solutions are relatively rigid and prescriptive as to how data is recorded as well as how it is viewed, limiting the ways in which individuals with chronic conditions can engage with their health data. These individuals have unique experiences with their conditions, symptoms, pain, treatments, and resulting lives. Each individual has a unique way in which they wish to engage with self-management and self-advocacy, affecting how they think about health information, impacting how they want to log and review it.

The existing landscape presents opportunities for research to explore ways to make data collection less obtrusive and less rigid, do more with less data entry, and enable flexible data visualizations that adapt to each individual's needs. More work also needs to be done to design these systems in iterative co-creation cycles with the individuals who will use them.

¹² Health Informatics. <https://medicine.yale.edu/seiche/research/health-informatics/>.

Project

Iterative design of tools and interfaces for understanding how adaptive strategies and other variables influence a chronic condition.

Overview

We will build a system that allows individuals to gather the data they need in one place for review. We will experiment with mechanisms and interfaces for data collection and interpretation, as described in our initial set of questions below. What we build may take the form of desktop or mobile apps, web apps, or new purpose-built devices. We will evaluate these concepts within the real lives of individuals with chronic conditions.

Informed by our prior research in human-computer interaction and bioethics, and by our experiences navigating life with a chronic condition, we will take a participatory health informatics approach in quick, iterative cycles. We will work one-on-one with individuals to unearth the deeper insights necessary to design supportive technology. We will work in the open, publishing regular “lab notes” that describe the concepts in our iterations and how they perform.

Phases

Most of our work will happen in one- and two-week iterations, in which we will design, develop, test, and review concepts in real use that help answer the core questions in our project.

In the first phase, we will conduct a field study of current solutions employed by individuals in interviews, and broadly explore initial designs for our experiments. This phase will also include the development of a flexible data storage framework that will support our work going forward. **2 - 3 weeks.**

For the first half of the project, we will work in iterations that explore concepts informed by the insights gathered, designing and developing the ones that have the most potential, testing and reviewing them in real use within the core research team. The primary aim of these iterations is to quickly refine our fundamental understanding of this problem space, discard dead-ends, and identify promising directions. **4 - 6 iterations over 6 weeks.**

For the second half of the project, we will work in similar iterations, testing promising concepts in real use with three to five individuals. The primary aim of this process is to identify what bottlenecks exist with the concepts employed, iterate on ways to resolve them, and improve the whole system. **4 - 6 iterations over 6 weeks.**

In the final phase of our project, we will prepare our findings for presentation, identifying in particular what challenged assumptions, surprises, and other insights we found to be impactful in this work. We will present the final concepts that we believe are most promising to empower individuals with chronic conditions in making more informed decisions with regard to their health and in advocating for improved support from their healthcare providers. **3 - 4 weeks.**

Total project duration: 4 - 5 months.

Questions

Our project aims to answer questions around 1) data collection, and 2) data interpretation. Many important questions will be surfaced during the course of the work, though we have identified some starting points:

1. How can data collection be made more empathetic and less obtrusive? How can more data be collected with less effort required by the individual? What methods increase the quantity and quality of data collected?

- How are individuals already logging their data? Is there a way to gather this data (e.g. written journal entries, health apps, etc.)? Can written journal entries be turned into structured data automatically?
- People don't need to be interrupted with their condition more than they already are. How can data be gathered empathetically without unnecessary intrusion?
- What potentially important data can be gathered without direct input (e.g. weather for the current location, physiological data from wearables, etc.)? Can EXIF data (metadata embedded in images) be

used to determine locations over time to retrieve more detailed weather information?

- What interactions allow individuals to input data more naturally, with higher fidelity, and less work (e.g. sketch current problem areas on body)?
- Can enough useful information about diet be discerned from simple photographs, without requiring tedious direct input?

2. How can data interpretation be made more flexible, so anyone can arrange data visualizations that surface meaningful answers to the questions that are most important to them?

- What are individuals with chronic conditions looking for? What kinds of questions do they have about their conditions? How do they want to test their hypotheses?
- What are caregivers looking for, if different? Are there unique needs when multiple caregivers are involved?
- How can people view independent, time-aligned data in visualizations that help them see the meaning within? How do we give them complete control over these visualizations?
- How can data from long spans of time be summarized in aggregate views to help people see the meaning within? How can individuals expand more detailed data from aggregate views?
- What should people see in data summaries? How can key factors that shouldn't get lost in aggregate summaries be identified?
- How can people be supported in interpreting and understanding correlates?
- How can people be supported by their personal data in preparing for and during doctor appointments?
- How effective is machine learning at identifying meaningful correlates?
- Can individuals use expert-made templates for explorable explanations¹³ with their personal data? Can individuals construct explorable explanations of their own?

Inclinations

The most important insights are the ones we will uncover through the course of our work with individuals in this project. We do have some inclinations to inform our initial experiments.

As individuals with chronic conditions already have to think about their conditions more than they'd like, we aim to reduce any added burdens to their day. We have some ways that we can begin experimenting with collecting meaningful data unobtrusively:

- **"No news is good news"** — Some explorations in data collection expect individuals to log health outcomes frequently, otherwise leaving gaps in the data. Individuals with chronic conditions inherently think about their disease and symptoms more when their health is worse; because of this, we can experiment with an approach that presumes a certain baseline (e.g. neutral or positive) when logging doesn't occur, reducing the burden placed on the individual.
- **In-context devices** — Some explorations in data collection ping individuals requesting input at specific times each day, via text message, email, or push notification. These might arrive while an individual is not well-suited to be bothered with this kind of reflection; instead, we can experiment with low-cost purpose-built devices that can be placed in appropriate contexts for regular input. For example, a small touchscreen device placed by the sink or in the closet where one prepares for the day could be used to provide the baseline measure of each day's wellness without obtrusion into life experiences that should otherwise go undisturbed.
- **Time-aligned data visualizations** — Bringing together independent data that's related by time is a simple but effective way to allow people to find connections they need to answer their key questions.¹⁴ This inclination is not well-supported by today's landscape of apps, which silo their particular domain of data, and further experimentation needs to be done with the interactions used.
- **Data providers** — What data is already generated everyday that can be used to glean important insights without the need for any additional data en-

¹³ Explorable explanation - Wikipedia. https://en.wikipedia.org/wiki/Explorable_explanation.

¹⁴ LN 038: Semantic zoom. <https://alexanderobenauer.com/labnotes/038/>.

try? Some examples: weather forecasts, meetings and travel in calendar events, activities from photos, time spent typing or on the computer, and additional metrics from mobile phones and wearables such as distance walked or hours slept. Further, what unstructured data about an individual's day can be transformed into structured data?

- **A focus on self-empowerment** — An interface that focuses solely on how bad someone feels won't be used for long. In order to be a durable tool in someone's life, it needs to be empowering; it needs to support the outcomes an individual most wants to see, and reinforce their hopes and progress.
- **No prescribed changes or judgments** — What we build will not push individuals to engage in any prescribed behavior changes. In reviewing prior art, we found many examples of health apps and research prototypes that strive to promote specific behavior changes, such as increased exercise or changes to diet. But the landscape for individuals with chronic conditions has many particulars. Every condition is different, and how each body responds to variables is different too. Our project will not make judgments or motivate any prescribed changes. Rather, our project specifically aims to empower individuals with an improved, data-supported understanding of their condition(s); to put the power in the hands of the individual to self-manage and self-advocate for their desired quality of life.

Approach

This project employs a participatory approach with individuals, giving us the opportunity to understand each person's experience, context, mindset, and motivations. In our iterative cycles working one-on-one with individuals, we will be able to listen intently and make quick adjustments that can then be tested further. We have found this to be the right approach with early concepts in human-computer interaction research.

What we build will not push individuals to engage in any prescribed behavior changes. Often, health apps and other research prototypes strive to promote specific behavior changes, such as increased exercise or changes to diet. Every condition is different, and how each body responds to variables is different too. Our project will not make judgments or motivate any particular changes. Rather, our project specifically aims to empower individuals with an improved, data-supported understanding of their conditions; to put the

power in the hands of the individual to self-manage and self-advocate for their desired quality of life.

We will publish "lab notes" at the end of most iterations that describe our latest experiment(s), the questions they seek to answer, and the results we've found so far. We've found working in the open to help route key resources and intersecting work to our inboxes, and help spark guiding conversations. We will continue that tradition with this project to benefit from the knowledge of the commons as we go, and contribute to it, rather than working in silence and only publishing at the end.

Broader applicability

Though our focus is on individuals with chronic conditions, much of what we discover and build is likely to have broader applicability which would inform future research.

Athletes and those who focus on their physical and mental health (fitness, nutrition, etc.) would likely find similar tools to be helpful, as the fundamentals of discerning how one's body responds to the variables in and out of one's control are the same. A future project with a focus on another population, such as athletes, might help unlock further insights that support those with chronic conditions as well.

This work would also support future exploration and larger-scale studies when looking at access to healthcare for the most marginalized populations including minorities and those in rural communities. Because of a diminished access to quality healthcare, these individuals often need to employ self-management and self-advocacy techniques at a higher rate than the general population, particularly when navigating chronic conditions.

More broadly, new interfaces for flexible data modeling in search of meaningful insights is a core component of this project; results here could help in many domains where interactive data interpretation is critical, from news and articles published for the public to interactive data notebooks used by scientists and other researchers.

Finally, an important part of our process is engaging in co-creation within iterative cycles. We will observe our process, seek to improve it, and share the knowledge gained. We've found processes like these to be critical for human-computer interaction research, particularly when working with early ideas, so insights gained here may contribute to a wide range of future work.

People

Sarah Obenauer is a researcher, designer, and writer. Her work focuses on inequalities in healthcare, particularly in regard to persons with disabilities and chronic conditions, and the right for autonomous decision-making in our healthcare systems. She is pursuing a Master of Science in Bioethics at Harvard Medical School.

Alexander Obenauer is a researcher, designer, and software engineer. His work in human-computer interaction explores user agency and end-user interface construction. His research focuses on the future of personal computing in search of transformative systems that better serve people's lives and work.

Lending a personal lens to this project, Sarah has lived with Rheumatoid Arthritis (RA) most of her life, having been diagnosed as a teenager. Navigating life with RA gives Sarah intimate insights into the problems described in this proposal, and the outcome of experiments with possible solutions.

This project will be advised by Dr. Alex Warth, a principal investigator at Ink & Switch. Previously, Dr. Warth was a principal investigator at HARC, a researcher at Viewpoints Research Institute, and an adjunct professor of computer science at UCLA.

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