

# Understanding Personal Informatics Needs of Individuals with Chronic Health Conditions

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## Abstract

*Personal informatics tools allow individuals to collect and reflect on data related to their personal lives. While consumer tools have mainly focused on everyday aspects of life, such as physical activity or personal finance, they may also provide value to individuals suffering from chronic health conditions. These individuals may have unique needs not yet addressed through the current design of personal informatics tools. We address this problem through an interview study with 15 individuals focused on those with chronic health conditions, in which we explored how data collection supported the management of their illnesses. We found that data collection gives these individuals a means to understand their conditions, as well as a mechanism to manage them.*

## Introduction

Personal informatics is the process of collecting and reflecting on personal data for understanding and self-discovery [1] in the pursuit of positive behaviour change. Recent research has explored the problems and needs of personal informatics enthusiasts in an effort to develop design requirements for data collection tools (e.g. [1–3]). However, individuals who collect data for health reasons may have different needs, for which current personal informatics tools may be inadequately designed. We developed and conducted an interview study with 11 participants with chronic illnesses who collected personal data, as well as 4 personal informatics enthusiasts without chronic illnesses.

## Findings

*Collected Data.* Some participants collected data about episodes (i.e. detectable incidents such as seizures or migraines). Some tracked indicators of the current state of their conditions (e.g. blood glucose concentration). Some tracked medication usage patterns and effectiveness. Some collected information about potential episode triggers.

*Tools.* Specialized tools provided by medical professionals typically were highly rigid and structured. Users felt their data was reliable and accurate, but were frustrated by a lack of flexibility. Some (mainly people collecting a wide variety of data) used notebooks – this provided maximal flexibility, but minimal structure. They appreciated the portability of notebooks, but found them comparatively cumbersome with the result that data collection was often unreliable or inconsistent. Some (mainly people with experience with other tools and thorough understanding of their own needs) used personalized templates for personal computer software. These provided flexibility, but also structure and analytic tools.

*Reflection.* Many participants lacked a meaningful way of reviewing data, due in part to the nature of the data collection tools. Interviews revealed they were interested in the understanding that a deep exploration of their data could provide, but did not know where to begin. The non-digital tools they were using did not provide support for reviewing the data in a form other than that it was collected. Even for participants who used digital tools, the visualizations provided were insufficient for their needs.

## Discussions

*Self-Management.* Chronic illnesses can be hard to adjust to living with. These of these conditions require constant care and monitoring, and self-management is inevitable. A combination of medication, eliminating triggers, and introducing preventative measures can lead to reduced symptoms and better quality of life. Participants in our study sought to improve their abilities to manage their conditions by seeking out *descriptive* and *personal knowledge*.

*Descriptive Knowledge:* This refers to the condition itself – its causes, treatment options, symptoms, triggers, and demands. Typically drawn from external sources (e.g. doctors, online resources, etc.), it is generic, unindividualized information describing the condition in general, but is not specific to the patient.

*Personal Knowledge:* This refers to an individualized understanding of how the condition impacts the individual personally. This enables individuals to take the knowledge provided by medical professionals and translate it to something meaningful to them personally, empowering them to take control of their own health. This understanding is supported by the data collection and reflection process.

*Doctor-Patient Communication & Tension.* Traditionally, medical professionals have been considered the only healthcare experts; new research suggests that there is value in considering patients as experts as well [4–6]. Treatment is no longer solely the province of doctors, as patients increasingly incorporate treatment into their daily lives. That said, while patients may be considered “experts” in understanding their own daily routines, they continue to require the education, experience and clinical knowledge of medical professionals. It is important that health data collection be undertaken in close consultation with medical professionals in order to prevent health risks.

### **Implications for Design**

*Scaffolded flexibility for preparation and collection.* Data collection tools should provide templates for necessary data, but also allow users the flexibility to subtract or add specific data elements as they gain greater familiarity with their conditions and collection processes. Tools should allow users to make use of the clinical knowledge of the medical community while seeking the personalized knowledge of their own data.

*Supporting personalized reflection with descriptive knowledge.* Review tools should employ analytic techniques that allow people to explore potential relationships between different types of data. These analytic tools should be informed by descriptive knowledge about the particular condition of the individual, moving beyond the use of pre-determined statistical extrapolation from historical patterns, towards a tailor-made analysis. In this way they draw attention to specific factors to explore based on an informed perspective, such as triggers that may cause episodes, or specific behaviours’ impacts on health indicators.

*Tools should ease the burden of data collection, but not necessarily through automation.* While participants found data collection burdensome, manual collection itself can be a source of insight and understanding. The determination of what modes of data collection make sense for specific applications will depend on a number of factors, including whether there is insight to be gained in having a person collect data manually, and whether there is a mechanism to collect data automatically. We can also address the burden in simple ways, such as automatically populating fields.

### **Recommendations for Further Investigation**

In this study we learned that patients are often instructed by physicians to collect data, or are sharing data with a team of medical professionals. We intend to conduct a follow-up study with medical professionals to understand the value they experience as they instruct their patients to collect data, and the problems they encounter when working with that data. Based on the challenges identified, we hope to provide recommendations for designing interfaces for personal informatics tools to support the needs of medical professionals as well as patients.

### **Conclusion**

The analyses of the results of this study have shown that individuals who are using a personal informatics tool to better understand and manage a health condition have different needs than the self-experimenter types of individuals studied in previous work. Individuals with critical health conditions seek knowledge about their condition, but also about how the condition impacts them individually.

### **References**

1. Li I, Dey A, Forlizzi J. A stage-based model of personal informatics systems. Proceedings of the 28th international conference on Human factors in computing systems [Internet]. New York, NY, USA: ACM; 2010 [cited 2012 Jan 20]. p. 557–66. Available from: <http://doi.acm.org/10.1145/1753326.1753409>
2. Li I, Dey AK, Forlizzi J. Understanding my data, myself: supporting self-reflection with ubicomp technologies. Proceedings of the 13th international conference on Ubiquitous computing. 2011. p. 405–14.
3. Consolvo S, McDonald DW, Landay JA. Theory-driven design strategies for technologies that support behavior change in everyday life. Proceedings of the 27th international conference on Human factors in computing systems. 2009. p. 405–14.
4. Ballegaard SA, Hansen TR, Kyng M. Healthcare in everyday life: designing healthcare services for daily life. Proceedings of the twenty-sixth annual SIGCHI conference on Human factors in computing systems. 2008. p. 1807–16.
5. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA: the journal of the American Medical Association. 2002;288(19):2469–75.
6. Mamykina L, Mynatt ED, Kaufman DR. Investigating health management practices of individuals with diabetes. Proceedings of the SIGCHI conference on Human Factors in computing systems. 2006. p. 927–36.