

Improving African Youth's Diabetes Self-Care Behaviors using a Paper-Based Diary Dr.

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Introduction

The incidence of type 1 diabetes (T1D) is increasing globally. Recent reports suggest that by 2025, 18.7 million people in Sub-Saharan Africa (SSA) will be affected by diabetes. In SSA, T1D is most frequently diagnosed in adolescents, or “youth” between 13-18 years old. Health technologies are available to help youth manage diabetes (e.g., mobile health applications); however, most of these interventions are designed for populations in high-income countries and rarely account for African youth's needs and context. To address this problem, the National Institutes of Health (NIH) funded our use of human-centered design (HCD) to develop an intervention for and with Kenyan youth. In collaboration with 24 youth, their caregivers, doctors at government health clinics, as well as the Kenyan Diabetes Management and Information Center (DMI) and a local design team, a paper based T1D diary was developed. The diary includes pages to record and chart daily glucose readings and contextually appropriate information, imagery, and advice. Findings from the formative evaluation of the diary suggest that regularly using it increases adherence to treatment regimes, knowledge of the disease, and youths' overall self-management of T1D. The purpose of this study is to further evaluate the diary's effects on youths' self-care behaviors (i.e., the actions people take to T1D on a daily basis to maintain glycemic control). To achieve this, a summative evaluation of the diary's effectiveness in improving youth's T1D self-care practices will be conducted. More broadly, results from this evaluation improve the diary, and guide the development of a final version to be distributed to +50,000 youth with T1D in Kenya and other African countries.

Purpose and Preliminary Research

The World Health Organization estimates that 50,000 to 70,000 Kenyan youth have T1D, but the actual prevalence among the country's youth is unknown. Comprehensive studies examining these adolescent's experiences with the disease are also scarce. Anecdotal evidence from DMI, and reports in Kenyan newspapers suggest that the incidence of T1D is rising, in the country and elsewhere in SSA (i.e., Tanzania). The rise in prevalence is concerning because T1D is a lifelong disease. Managing the illness is intensive, expensive, and relentless. This is especially true for adolescents, who encounter challenges managing the disease at this developmental stage (e.g., social stigma). However, if well-managed diabetic youth can enjoy a reasonable standard of living. Health technologies can support self-management of the disease. In the United States, and other high-income countries, there are +300 mobile health applications (or mHealth apps) that support diabetes management (e.g., Glucose Buddy, mySugr, and On-Track Diabetes). Many of these smartphone apps act as a blood glucose diary. They allow users to log glucose readings, daily eating behaviors, medication compliance, physical activity, and emotional well-being. Studies of these apps suggest that using them can increase the frequency of blood glucose monitoring, knowledge of the disease, and that they generally improve the lives of people with diabetes. However, the benefits of these health technologies have not reached youth in other parts of the world, including in SSA, where their uptake is limited. Many factors contribute to the limited adoption of these services; in particular, they rarely—if ever—are designed to account for SSA youths' needs and context. Human-centered design (HCD) is a promising strategy increasingly used to develop contextually relevant health interventions. The HCD process is typically made up of three broad stages: **understanding**, **ideation**, and **implementation**. These stages guided our NIH-supported project.

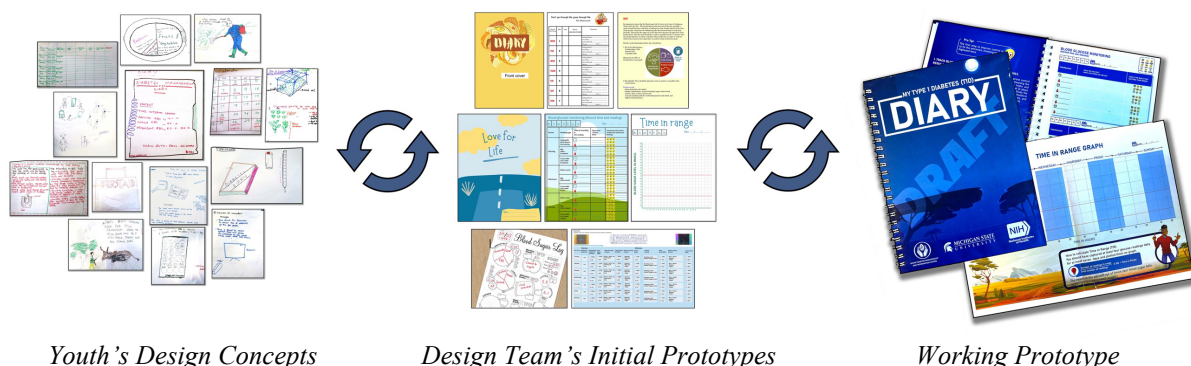


Figure 1

The diary is the outcome of a +2 year collaborative research and design process, between MSU researchers, Kenyan youth, their caregivers, as well as diabetes health experts (affiliated with DMI and government health clinics) and designers. During our study's **understanding**, or formative research phase we interviewed 24 youth, their caregivers, and other key informants (e.g., teachers and school nurses who regularly interact with youth with T1D). We conducted these sessions in April 2022 at a rural and an urban site in Kenya: Vihiga County and Nairobi. Findings from our analysis, suggest that youth, and their caregivers, are generally lacking knowledge of T1D until after diagnosis. As reported in prior studies, the youth in our sample were typically diagnosed late in relation to symptom onset, and often after admission to hospital with severe complications (e.g., prolonged and extreme hypoglycemia) [3]. However, over time, most youth and their caregivers gained sufficient knowledge and understanding of T1D; they also learned how to manage their illness. The youth in our study understood the importance of regularly testing their glucose, eating a healthy diet, and exercising. We also learned that none of our participants used mHealth apps. Multiple reasons contributed to this finding, including participants not owning a smartphone. Participants who had mobile phones, typically owned a simple feature phone. They rarely used these devices because they typically lacked airtime/credit, a charged battery, and/or the phone was “spoiled” or broken. Other factors contributed to youth not using mobile devices to manage their T1D, notably, that the devices are banned in Kenyan schools, as is the case in many SSA countries.

We also learned that youth and their caregivers have ideas about how to improve their T1D self-care practices. In July 2022, we held two “design workshops” with the same 24 youth and their caregivers who participated in our study’s understanding phase. A key objective of our project’s **ideation** phase was to identify an intervention that would support youth’s T1D self-management. We asked participants to brainstorm, draw and then present their design ideas. Workshop outcomes included a dozen sketched concepts (see Figure 1; left). After the workshops, our team met to discuss these concepts; we agreed that designing a personal diary was a promising solution. Next, we developed guidelines for the diary; these were based on learnings from the workshops. Guidelines included: designing a fun and inviting cover; featuring emojis (to communicate emotions); adding a “time in range” chart¹; and incorporating writing spaces into the diary where youth can reflect on their management of the disease. The design team used these guidelines to develop three initial diary prototypes (Figure 1; center).

The final phase of the HCD process is **implementation**, or the project’s formative evaluation phase. In September 2022, we gave the prototype diary (Figure 1; right) to the youth, their caregivers, and other stakeholders who contributed to its development (e.g., doctors, and community health workers). Our goal was to validate the intervention’s usefulness as well as the feasibility of using it to increase adolescents’ knowledge of T1D and management of the disease. To achieve this goal, we conducted focus groups to assess youth’s initial reactions to the diary, asked them to fill out pages (e.g., blood glucose monitoring page), and solicited feedback on the diary’s strengths and weaknesses. We also administered a short survey to assess how often the diary was used during a one-month period. Participants’ feedback was generally positive. They commented on the diary’s professional appearance and noted the inclusion of images that were similar to their context (e.g., illustrations of foods they ate). We also received significant feedback on how to improve the diary. This included adding more information about how to properly store insulin—when you do not have access to a refrigerator—as well as guidance on how to best inject insulin. Survey data

¹ Time in range is typically depicted as a bar graph that shows the percentage of time over a specific amount of time when blood glucose was low, in range, and high. This data is helpful in finding out which types of foods and what activity level causes blood glucose to rise and fall.

suggested frequent use of the diary (i.e., at least once a day). Further, a formal launch of the diary received high level government attention and press coverage². DMI is seeking to incorporate the diary into Kenya's T1D management protocol and distribute it to all youth with T1D in the country.

Proposed Study: Summative Evaluation of Paper-Based T1D Diary

This proposed study builds upon our NIH-funded project, the diary titled *My Journal to Better Health: Type 1 Diabetes Diary for Kenyan Youth*. In this diary, Kenyan youth can record and graph their glucose levels, note insulin injections, document food intake, activities, and express moods with emojis. By “connecting the dots,” they learn how their glucose levels and mood are affected by insulin, food, and activities. The diary also contains educational content, including “myth busters.” Our intervention underwent several iterations involving youth, DMI, government T1D medical staff, and the design team, fostering a strong sense of ownership among Kenyans. However, the actual impact on youths' knowledge, behavior, and well-being remains unknown. A formal evaluation is necessary before widespread distribution. The primary goal of this study is to assess the diary's effectiveness in improving T1D self-care behaviors. Our broader objective is to use this information to develop a final version for distribution to youth in Kenya and elsewhere in East Africa.

Self-care is a crucial aspect of T1D management, defined as an evolutionary process of developing knowledge or awareness by learning to survive with the complex nature of diabetes in a social context. T1D self-care behaviors encompass healthy eating, physical activity, medication adherence, disease education, problem-solving, and monitoring. Our diary is designed to support these behaviors, providing space for recording blood sugar levels, weekly reflections on self-care, and information on managing the illness. Self-care interventions empower individuals and communities to manage health and well-being. We hypothesize that daily use of the diary will enhance self-care behaviors among youth with T1D by promoting compliance with recommended care and expanding disease knowledge.

The following questions will guide our evaluation:

- Did using the diary improve youth's self-care practices?
- How does the diary compare to other recording mechanisms (e.g., notebooks and other paper-based methods)?
- What diary design features support these practices (Time in Range graph, weekly reflections, emojis, educational content, etc.)?
- Do changes in self-care behaviors vary by youth's characteristics (e.g., age, rural or urban)?
- What changes are needed, so we can scale the diary to other African countries?

We will employ a mixed-methods and quasi-experimental approach to answer these questions. Collaborating with DMI, we will identify statistically similar groups of youth aged 13-18 with T1D in Kenya. The study will commence with baseline surveys for both experimental and control groups to assess participants' self-care practices. The experimental group will receive the diary for one year, while the control group will not. An endline survey will be administered at the study's conclusion to measure changes in self-care behaviors.

For an in-depth understanding of the diary program, we will collect qualitative data to complement the survey data. Qualitative methods may include ethnographic interviewing, key-informant interviews, and focus group discussions. Qualitative inquiry will occur at the midline of the evaluation, following initial survey analyses, and at the study's end. We will triangulate quantitative and qualitative data to gain a detailed understanding of the diary's effects on Kenyan youths' self-care.

Project outcomes will include a comprehensive understanding of how Kenyan adolescents with T1D manage the disease and design guidelines that will inform the final version of the diary. In collaboration with our local design team and DMI, we will implement the final changes to the diary and distribute it to over 50,000 youth in Sub-Saharan Africa.

² WESTV (May 5, 2023). *Type 1 Diabetes* [YouTube Video]. <https://www.youtube.com/watch?v=Lg8Ii1ulRyk>