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Final Consulting Report

Incentivized Activity Monitoring in Jamaica

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August 2021

Carnegie Mellon University

cmu.edu/tcingc

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August 9, 2021

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The University Hospital of the West Indies
Technology Consulting in the Global Community (Carnegie Mellon University)

EXECUTIVE SUMMARY

Diabetes in Jamaica is described as an epidemic as it is found in 12% of the population who are 15 years or older, and it is the leading cause of death of women in Jamaica.[1] Habit formation with regards to increased physical activity is not only critical in addressing this problem but is a low-cost way for people with diabetes to make changes in their lifestyles. Because of this, the University Hospital of the West Indies (UHWI) seeks to encourage additional patient physical activity to decrease care cost and help create a healthier nation at large through the development of digital financial incentives. To capture the relationships between monetary incentives, increased physical activity, and improved health indicators, UHWI is partnering with Brandeis University in Massachusetts. Under Dr. Donald Shepard (Professor of Health Economics at Brandeis' Heller School for Policy and Management), a study is being planned to determine whether changes in health status (through increased exercise) reduce care costs and complications related to diabetes. Known as Incentivized Activity Monitoring in Jamaica (IAMJ), the study will make the initial steps to bridge a digital gap at the Diabetes Clinic at the UHWI by providing step count collection infrastructure but hopes to ultimately make a difference in the lives of Jamaican diabetes patients in the long term. This report describes the work of a joint American-Jamaican team of three student consultants over the summer of 2021 to develop key elements of the software and procedures.

[1] "Interim Guidelines for the Clinical Management of Diabetes in Jamaica." *Ministry of Health and Wellness:* August 2020

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I. Background Information

1. Organization Overview

The University Hospital of the West Indies (UHWI) is the hospital affiliated with the University of the West Indies (UWI) in Kingston, Jamaica. The hospital was created to supplement the medical students housed by the university. It currently serves the purpose of facilitating clinical training of health care professionals. The UHWI consists of departments that provide many services- including clinical (cardiology, endocrinology, nephrology, etc) and non-clinical.[2] This research project is in collaboration with the diabetes clinic within UHWI. The mission statement of the University Hospital of the West Indies is the following:

> *The University Hospital of the West Indies is committed to teaching, research and the provision of quality health care for the region. In striving for excellence, it maintains an environment conducive to an efficient, cost effective, responsive health care promotion and delivery system by incorporating the participation of all categories of staff and students, patients, their families, and the wider community.*

The UHWI diabetes clinic is led by one lead doctor known as a consultant, 4-5 doctors in training, and 2-3 nurses. The clinic receives occasional help from dietitians, and there is one full-time administrative assistant who enters patient data at check-in as well as at the end of the clinic encounter. Because UHWI is a hybrid private/public hospital, some of its funding comes from the Jamaican government and some comes from donations.[3]

2. Stakeholders

There are many staff members from all parties involved in the project who have helped and will continue to help the project group.

On the University Hospital side, Dr. Michael Boyne and Dr. Patrice Francis-Emmanuel are endocrinologists engaging with the diabetic patients of the clinic. Their expertise includes health data measurement, patient health behavior/lifestyle habits, and patient/clinic resources. Mr. Wayne Little is the technical assistant for the solutions team at the UHWI, and our main point of contact with the IT Department. He is familiar with the architecture behind the software used by UHWI and the stack needed to create/maintain new applications.

At Brandeis University, there are Dr. Shepard and research assistant Amanda McCleary. They have provided insightful information regarding research literature, the background and motivation of the study, project timeline, and project funding.

Lastly, at the University of Technology, Jamaica, we are working with Dr Lisa Facey-Shaw and Dr. Christine Fray-Aiken. Dr. Facey-Shaw served as a faculty advisor to the

[2] Jamaica Information Service, Official Website of the University Hospital of West Indies.[3] Dr. Patrice Francis-Emmanuel. Personal Interview, 10 June 2021.

[3] Dr. Patrice Francis-Emmanuel. Personal Interview, 10 June 2021.

group, while Dr. Fray-Aiken's experience in running international research projects gave guidance into financial matters around research participants and students in the Jamaican context. Dr Fray-Aiken's expertise is in nutrition and nutrition economics.

Study Participants

Over the summer of 2021, a pilot program was conducted for the study with 3 volunteers from the UHWI Diabetes Clinic. The pilot program participants (PPP) were selected on a volunteer-basis only through the Diabetes Clinic. Two of the PPP were female, and one was male. Their ages range between 42 and 61 years. This range is reflective of the expected age range for a larger study. One participant has a smart phone compatible with the Fitbit application, and all the participants used a OneTweak pedometer to track daily step count.[4] Based on the PPP, the main conclusions to be carried into larger studies in the future are as follows:

- **Establish expectations from the beginning.** To encourage greater participation, establish a timeline with the participants so they know exactly when they will receive incentives to directly link participation to incentives. For example, at the end of the study, communicate clearly to the participants that if they meet the step goal for all 7 days of the week, they will receive 250 Jamaican dollars in phone credits on Sunday evenings at 8pm.
- **Find study participants in the Kingston Metropolitan area.** For the summer pilot program, volunteers come from parishes all over Jamaica. For their travels to the UHWI Diabetes Clinic, travel money was provided. For the larger study, it may be more cost effective to get participants that live in the Kingston Metropolitan area.
- **Maintain daily communication.** Over the summer, receiving step count from the participants ranged from reporting 100% of the day to reporting 25% of the time. The range of preferred communication methods differs greatly among participants (between email, text messaging, phone calls, etc), so maintaining regular communication is critical.
- **Determine if participants have a smartphone that is compatible with the Fitbit application.** One of the major take-away points from the summer pilot program is that only certain "smart phones" have internal accelerometers that track step count and communicate with the Fitbit application.[5] It is critical that if future studies want to use the Fitbit application as a way to track steps automatically, inclusion criteria for the study must be a phone with Android OS 8.0 or higher or Apple iOS 13.0 or higher.

[4] "Top 10 Pedometers Reviewed and Rated in 2021." *Garage Gym Builder*. January 7, 2021. Web. Accessed June 27, 2021. Web.
OneTweak was selected among a group of pedometers after a few weeks of research and testing to determine the best fit for the study. Ultimately, the most important features were easy to carry / attach to a waistband, cost, and storage of previous days' data. OneTweak has a 30-day history of the step counts, so if a participant forgets to send in their count on certain days, they can retroactively their data to send into the study. The one drawback of the OneTweak is difficult-to-follow instructions. This risk was mitigated by building a study-internal guide to using and setting up the pedometer.

[5] "Fitbit-Compatible Devices". *Fitbit.* Accessed July 25, 2021. Web.

3. Technology Overview

This study incorporates industry-specific terms from both the medical field and software development. Prior to detailing the current technology used by UHWI, several common definitions are given below:

- Application Programming Interface (API): part of the information storage system (servers) at an organization that receives requests and sends responses. There are several types, but it is ideal that APIs are open in order to facilitate software development[6]. It is a type of software interface, offering a service to other pieces of software. A document or standard that describes how to build such a connection or interface is called an API specification.[7]
- Electronic Health Records (EHR): information from all clinicians involved in a patient's care; all a patient's information contained in one centralized location[8]
- Electronic Medical Records (EMR): digital versions of paper charts from a clinic or hospital used for diagnosis or treatment[9]
- Personal Health Records (PHR): medications, medical history, immunizations, and other information that is managed by the patient themselves.[10]
- Open source: software people can modify, share, and update because it is publicly available[11].
- RESTful API: An API that conforms to the "REST" (REpresentational State Transfer) architecture. This is useful because it means that clients send information to the API / servers in a format via HTTP (HyperText Transfer Protocol)[12]; in short, it is easier to work with because it follows a standard set of programming guidelines.
- Software stack: a collection of independent components that support the execution of an application[13]
- User interface (UI): means with which person interacts with a software (typically in an intuitive way)[14]

[6] Petr Gasarov. "What is an API?" *Free Code Camp.* December 19, 2019. Accessed June 14, 2021. Web.

[7] "API." *Wikipedia.* Accessed August 9, 2021. Web

[8] "What are the differences between electronic medical records, electronic health records, and personal health records?" *HealthIT.gov:* May 2, 2019. Accessed July 21, 2021.

[9] Ibid.

[10] Ibid.

[11] "What is Open Source?" *Opensource.com*. Accessed June 14, 2021. Web.

[12] "What is REST API?" *RedHat.* May 8, 2020. Accessed June 14, 2021. Web.

[13] Margie Semilof. "Software Stack." *Tech Target.* Accessed June 14, 2021. Web.

[14] "User Interface." *Technical Terms.* Accessed June 14, 2021. Web.

Currently, the UHWI clinicians use an EHR known as the Health Information Management System (HiMS). The system consists of a web form in the front end for the staff members to fill out, as shown in Figure 1.[15] The information is stored in a database integrated and handled by HiMS: the architecture behind HIMS is done on Microsoft SQL Server on dotnet core. The IT department at UHWI has no way to access or manipulate this data outside of the HiMS interface.[16]

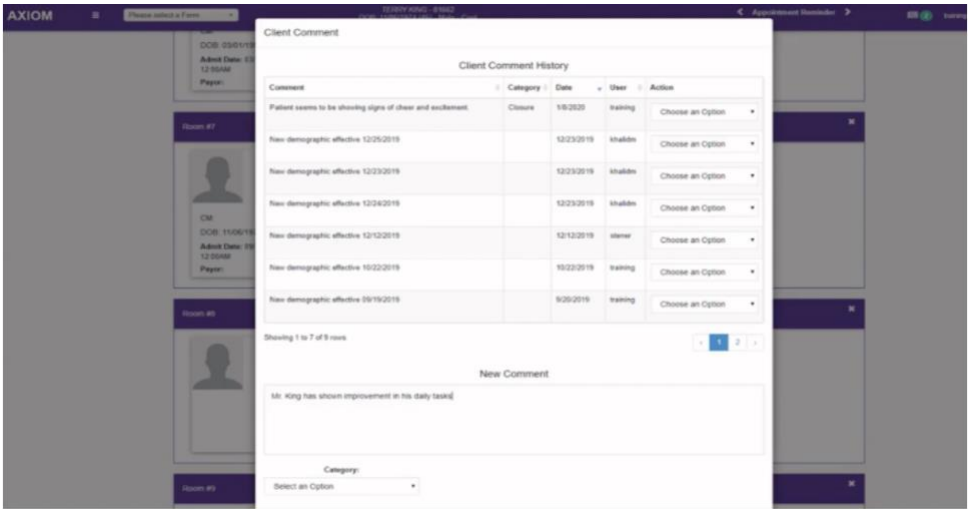

Figure 1: Example of Axiom Health Integrated Management System (HiMS)

The UHWI technical staff is in the process of phasing out software based on the Microsoft Software Library in favor of Linux-based systems in order to facilitate more internal software development. The IT Department staff prefers to minimize custom software: most of the productivity software is licensed from certified third-party vendors for a subscription fee. The purpose of this decision is saving development time to facilitate a wider range of projects across the hospital.

Table 1 details the current software stack employed both by the UHWI and by the summer student team for the IAMJ program. Section II (Current Capabilities and Findings to Date) goes into more details on the capabilities of these platforms; in short, the greatest strength of this software stack is the ability to make changes and updates without a formal coding education (as Xano and Appgyver are no-code platforms). However, the drawback is the lack of flexibility and customization.

[15] "AXiOM EHR", *Health Information System Management Systems.* Accessed June 14, 2021. Web.

[16] Wayne Little. Personal Interview, 09 June 2021

Name (Version)	Usage	Notes
Xano (Business Subscription)	Data Transformation	Flexible, transforms data from one source to another[17]; currently used at UHWI to connect Twilio with Appgyver for application development
PostgreSQL Database	Database	Used by Xano to store data[18]; open source, so easier to manipulate
Google Data Studio	Data Analysis	Used to convert data presented in a google sheet form into informative dashboards and visualizations.
Appgyver	Create UI	Used to create mobile, web, and other applications
DigitalOcean	Cloud-based data storage	Would be used to store data if the capabilities of Xano are insufficient for the data necessary in the expanded study.[19]
Twilio	Messaging	Services of choice used to send automated/incremental messages and mobile notifications to patients and staff workers.

Table 1: Software platforms used by UHWI

[17] "The Fastest No-Code Backend Dev Platform." *Xano.* Accessed June 14, 2021. Web.

[18] "What is PostgreSQL?" *PostgreSQL Tutorial.* Accessed June 14, 2021. Web.

[19] "Digital Ocean." *Digital Ocean.* Accessed June 14, 2021. Web.

II. Current Capabilities and Findings to Date

1. Motivation

The overall expected outcome for the IAMJ research team during the summer of 2021 is to increase the health of Jamaican diabetes patients by developing a framework to collect and incentivize daily step count. This goal has the potential to improve health indicators without a large up-front cost from the perspective of the researchers or clinicians. Another key to the goal is "developing the framework." The study during the summer of 2021 only collected data for three participants, but the infrastructure was designed in such a way that the study could be expanded in the future to a larger number of participants.

The study is focusing on reducing risk and complications related to diabetes; to help predict complications in diabetes and similar diseases, risk equations are often used. This study will utilize the Risk Equation for Complications of Type 2 Diabetes (RECODe) which was validated in the 2018 study by Basu et. al.[20] to guide health management decision making. The equation includes four input areas: demographics, clinical features, medical utilization, and biomarkers. Methods for capturing data from these areas are detailed in the Current Capabilities Section.

2. Current Capabilities

The capabilities of the study can be divided between technical and study design developments made by the student consultants over the summer. The technical capabilities are the in-processing website, the clinician dashboard, automatic step collection using the Fitbit OAuth2.0 process, and step collection using Twilio for low-tech study participants. The study design capabilities currently are three weeks of data collection for the pilot program participants, division of the incentives frequency and structure, and incorporated aspects of the RECODe equation.

Technical Capabilities

- **Study participant in-processing web application[21].** This website has four main functions. The first is to gain basic demographic information (such as age and gender). The initial set of questions also will also help researchers to determine what kind of phone the participants own and whether they fall in the "high-tech" (Fitbit compatible smartphone) category or "low tech" (steps will be strictly tracked using a pedometer) category. Contact information (phone number and email address) are collected to facilitate ease of communication with the participants throughout the study.

[20] Basu, Sanjay, J.B. Sussman, S.A. Berkowitz, R.A. Hayward, A.G. Bertoni, A. Correa, S. Mwasongwe, and J.S. Yudkin. "Validation of Risk Equation for Complications of Type 2 Diabetes (RECODe) Using Individual Participant Data from Diverse Longitudinal Cohorts in the U.S." *Diabetes Care:* Volume 41, March 2018. Accessed July 27, 2021.

[21] URL for participant web application: https://iamjpatient.appgyverapp.com/

The second functionality is to create a Fitbit account. This directs the participant to the Fitbit website to enter basic health information, an email address, and to create a password. This step can be skipped if the participant does not own a compatible smartphone or if they already own a Fitbit account.
If / when a Fitbit account is created by the participant, the third functionality is to give account access to the researchers. The participants can select which data the researchers and clinicians can see, but a requirement for the study is that they allow access to their activity. Once they allow access, an access and refresh token[22] are stored in the Xano database to allow for future access.
The fourth and final functionality of the participant in-processing website is to get a digital signature from the patients agreeing to participate in the program. The website has a basic privacy agreement that details the information they are agreeing to share with the study. Their digital signature is stored as their full legal name in the Xano database.

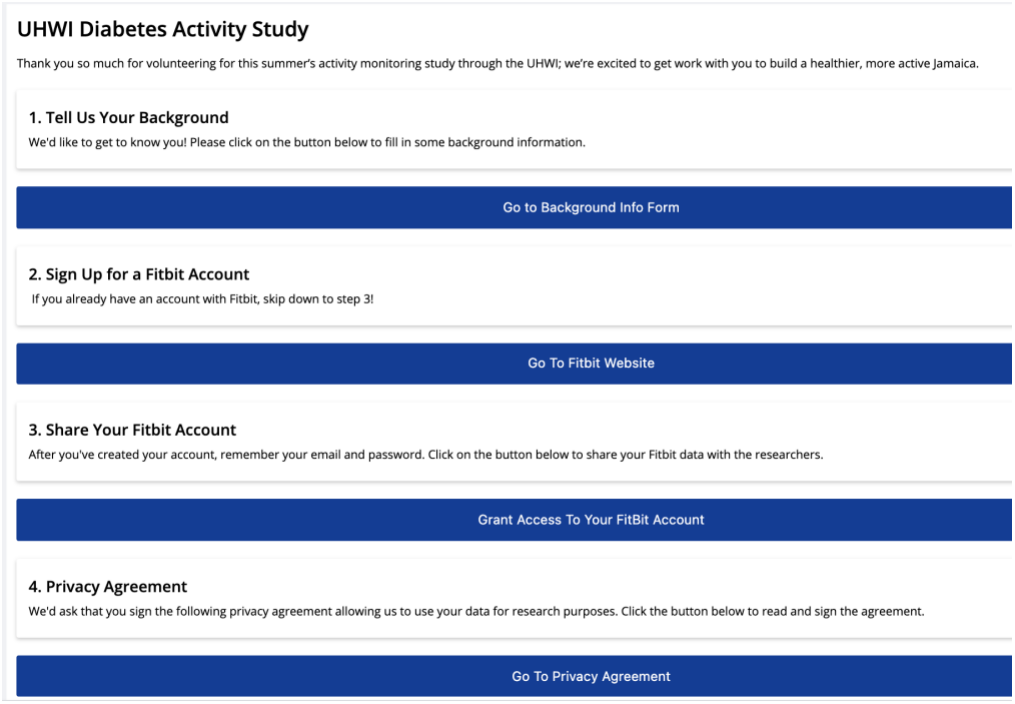

Figure 2: Patient In-Processing Home Screen

[22] "Accessing the Fitbit API." *Fitbit Developer*. 2020. Accessed July 27, 2021. Web

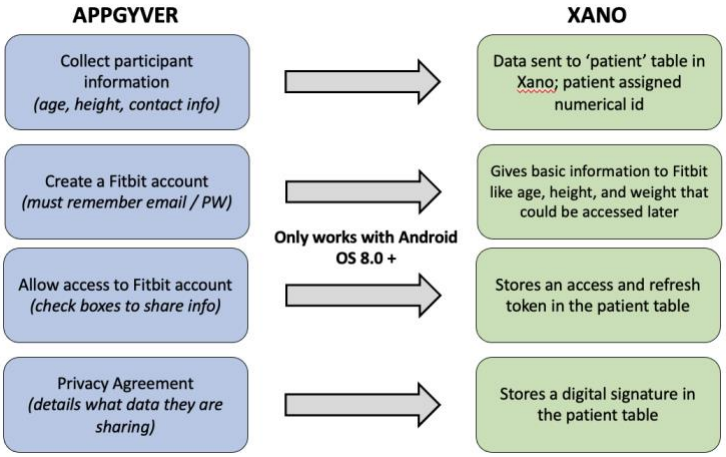

Figure 3: In-Processing Website Data Flow

- **Clinician / researcher dashboard web application[23].** This web application contains three main functionalities: user authentication, multiple views, and the ability to enter and update health information.
  The application is secured with an email/password login system. Email authentication is currently not implemented as of the end of the consulting team's tenure with the project, but the user interface also does not allow signups; the onboarding users for the dashboard is done internally.
  Following the login is the ability to navigate through the clinician or researcher's view depending on the role the user has in the study (the two roles have different use cases). The clinician's interface satisfies the following use cases: tracking daily step counts, monitoring weekly incentives, viewing health information history, adding new health visits, editing health data, viewing latest health visit and A1C test dates, automatic BMI calculations, and more. The technical team that takes over the project team's work will most likely make only minor modifications on this portion of the dashboard.
  By the end of the partnership involving the student consulting team, the research dashboard will remain mostly unpolished- and the volunteer medical students (as well as the UHWI's IT staff) will be responsible for finishing it. Ample resources and documentation will be provided from the student consultants to ensure the project timeline does not delay due to this transition.

- **Automatic step collection using Fitbit OAuth2 and API calls.** Developing an application that accesses information from Fitbit requires OAuth2.0 for "…user authorization and API authentication."[24] The best way to think of this process is when you give an application permission to access your data on Fitbit, you give them a username (access token) and a password (refresh token). The username (access token) expires after a certain amount of time to maintain security (in the case of the study, every eight hours). To access Fitbit data after the access token has expired, the refresh

[23] Clinician Dashboard: https://iamj.appgyverapp.com

[24] Ibid.

token is sent to Fitbit to request a completely new access and refresh token. Then, the application can pull data once again with the updated credentials. Both tasks were automated in the Xano database using Xano's built-in capabilities as shown in the figure below.

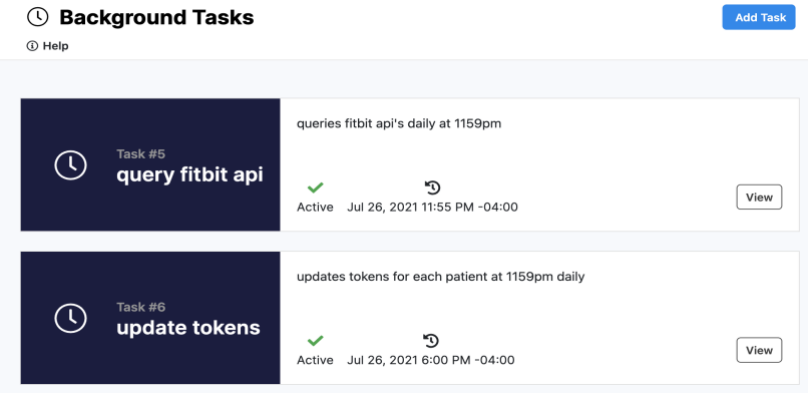

Figure 4: Background Step Count Tasks in Xano

- **Step collection using Twilio to Xano for low tech participants**. Most individuals in the pilot program do not have a high-end smartphone that supports the Fitbit application. To mitigate this risk and ensure the study can maintain a wide pool of participants, participants without a compatible smartphone carry a pedometer to count steps. To get the step count daily, an automated message reminder is sent daily using Twilio, a messaging service that communicates with the Xano database. The participants reply with the integer number of steps they took, and the number is added directly to the database. Participant phone numbers are collected during the sign0up process; by filtering by phone number, the step count received can be attributed to the correct participant.

Study Design

- **Three weeks of data collection with pilot program participants (PPP).** To test how data collection, communication, and incentives would work with the participants, the consultants working over the summer were able to get three weeks of data collection to help refine the study design. After speaking with researchers who had conducted similar studies on their communication patterns,[25] the initial data collection over the summer verified that consistent and regular communication is critical to maintain engagement with the study participants. During the summer study, manual communication was maintained daily with the PPP through the mobile application, WhatsApp. This is the messaging application used by most Jamaicans, and therefore the one that the PPP were most comfortable with. Additionally, a weekly feedback form was sent out to the participants with basic questions on how the study was going and any changes they would like to see (see Figure 4). This gave the PPP the chance to have

[25] Jane Ebert. Personal interview. June 8th, 2021.

an influence over the study design to make it better for the larger study. Finally, the summer consultants began to test data visualization methods to give the clinicians and researchers an easy way to view PPP progress over time (see Figure 5). Determining whether participants have higher activity levels over the weekend as compared to the weekdays is a possible area of future study.

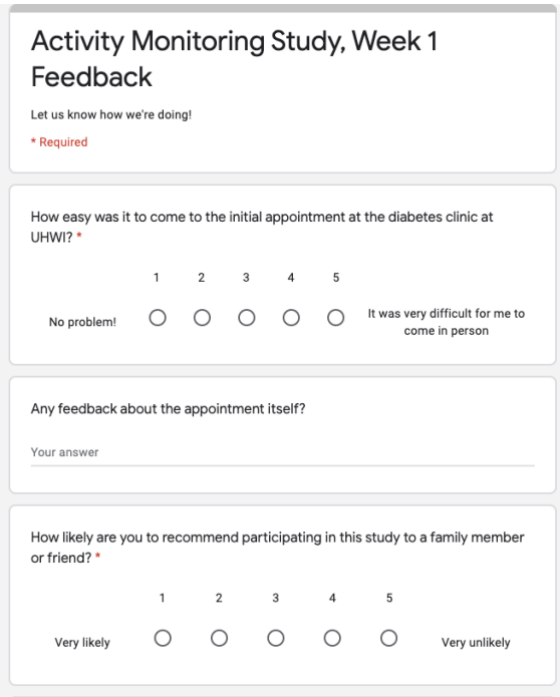

Figure 5: Participant Weekly Feedback Form

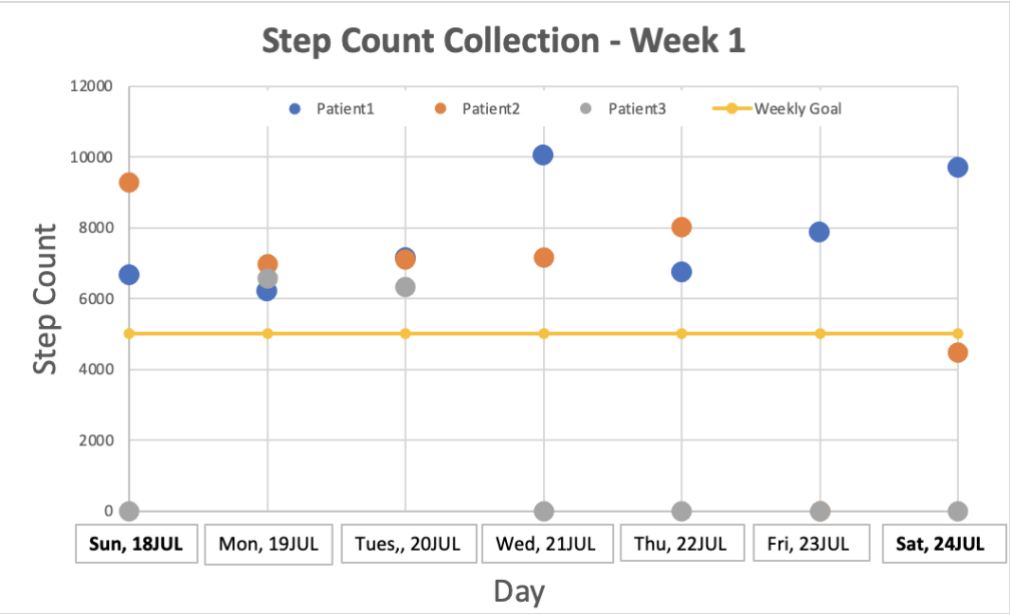

Figure 6: PPP Step Count Example

- **Develop incentives structure to capture participation, step count, and A1C levels.** Throughout the study, there were three main areas that the study stakeholders wanted to incentives: regular participation (sending in data and agreeing to participate in the study), meeting the weekly step goal (to be increased incrementally over time), and A1C levels (a blood test for measuring average blood sugar level over time[26]). The participation incentive will be used for both the treatment and control group to encourage participants to send in data and continue participating in the study. The step count goal will start at 5000 daily steps and increase incrementally each week. Finally, A1C is measured every three months, so participants will have three A1C readings over a six-month study. The incentives structure and plan is shown in Figure 7 below.

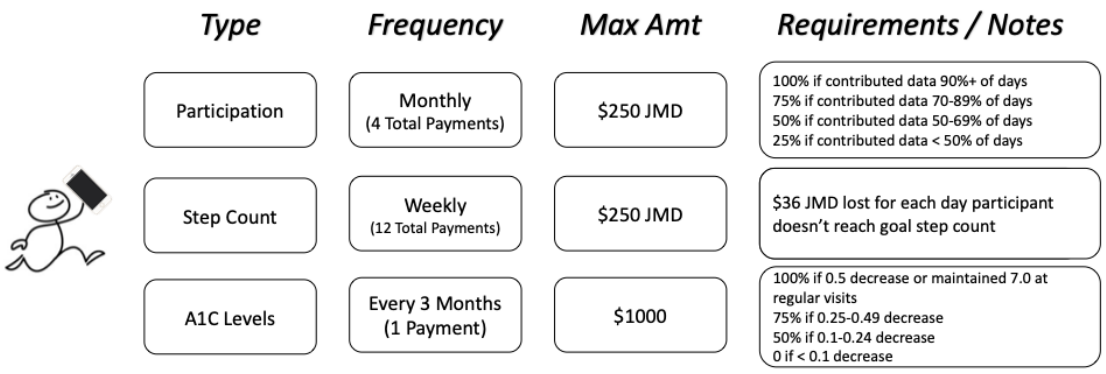

Figure 7: Incentives Structure

- **Incorporating RECODe equation into study design.** A key part of the study design is collecting data that allows researchers to efficiently translate data into the RECODe equation. The Basu study indicated three four major areas as shown in Figure 8: demographics, clinical features, medication utilization, and biomarkers. Based on the development and research of the summer student team, demographic information is collected on the patient in-processing website, clinical features and medication utilization are inputted to the database by clinicians in real-time, and biomarkers are inputted retroactively by clinicians following bloodwork.

Table 1—Characteristics of the MESA (2000–2012, *n* = 1,555 people with type 2 diabetes) and JHS (2000–2012, *n* = 1,746 people with type 2 diabetes) study participants included for validation of RECODe equations

	Included sample	
	MESA (*n* = 1,555)	JHS (*n* = 1,746)
Demographics		
Age, mean (SD), years	63.0 (9.7)	58.8 (11.0)
Women	772 (49.6)	1,136 (65.1)
Race/ethnicity		
White race	369 (23.7)	0 (0)
Black race	548 (35.2)	1,746 (100.0)
Asian race	187 (12.0)	0 (0)
Hispanic or Latino ethnic group	451 (29.0)	0 (0)
Clinical features		
Tobacco smoking, current	195 (12.5)	197 (11.3)
Systolic blood pressure, mean (SD), mmHg	131.7 (21.4)	130.3 (16.9)
CVD history	0 (0)	191 (15.1)
Medication utilization		
Blood pressure treatment	857 (55.1)	1,223 (71.9)
Oral diabetes medication (including metformin)	664 (42.7)	573 (33.7)
Statin use	351 (22.6)	349 (20.5)
Anticoagulant use	11 (0.7)	Not assessed
Biomarkers, mean (SD)		
Hemoglobin A_{1c}, % [mmol/mol]	6.8 (1.5) [51 (11)]	7.1 (1.7) [53 (13)]
Total cholesterol, mmol/L [mg/dL]	4.9 (1.0) [191.1 (38.4)]	5.0 (1.0) [194.5 (39.7)]
Direct HDL cholesterol, mmol/L [mg/dL]	1.2 (0.3) [46.3 (12.5)]	1.3 (0.3) [51.3 (13.5)]
Serum creatinine, μmol/L [mg/dL]	88.4 (35.4) [1.0 (0.4)]	88.4 (62.0) [1.0 (0.7)]
Urine albumin-to-creatinine, mg/mmol [mg/g]	7.6 (35.7) [66.9 (316.2)]	14.7 (58.2) [129.0 (515.6)]

Data are *n* (%) unless stated otherwise.

Figure 8: RECODe Equation

[26] "It's called the A1C test, and it's a powerhouse." *American Diabetes Association.* Accessed August 5, 2021. Web.

3. Feasibility and Sustainability

The proposed study framework is organizationally, technically, and economically feasible[27] due to the factors below.

There are three groups within the study's organization involved in sustaining the study: the UHWI practitioners, UHWI medical students, and Brandeis researchers. For each, the study is not their only priority or job, so it was important that the summer consultants developed the study framework in a way that made it easy for these three groups to continue the work. The three main areas of responsibility for these groups will be continuing communication with the PPP, expanding the study to suit a larger group of participants, and securing funding through the Jamaican National Health Fund (NHF) or the Inter-American Development Bank (IDB). Because the data collection, communication, and incentives structure has been established, the maintenance of the study is organizationally feasible.

Two aspects of the current study state make it technically feasible: its use of no-code platforms for both the front and back ends and its use of the same software stack as the UHWI IT Department. While Xano and Appgyver have some significant drawbacks when it comes to flexibility and ability to perform a wide variety of tasks[28], for the purposes of this study, they provide a basic set of functions. The platforms are well documented[29], and Xano has a sturdy system of office hours and support to provide help to people with no coding or software development background. Because of this, the medical student team can sustain the current software stack if not continue developing to make it better. Because the UHWI IT Department has full access to both the front end (Appgyver) and back end (Xano) of the study, if practitioners wanted additional functionality, the IT Department could assist in development. [30]

Finally, the project is economically feasible. The summer consultants explored a wide variety of options for step tracking and data storage to determine the best fit for this study. Other studies have used wearable watch technology, but to save costs, an infrastructure has been developed that does require any set-up costs for participants with a smartphone that meets the requirements. Additional costs will be incurred by the study in buying pedometers to include study participants that do not have a smart phone with an accelerometer. This reduces the chances of omitted variable bias in the study design (i.e., smartphone quality linked to economic status which could affect other health indicators).

[27] "Feasibility Analysis: Meaning, Importance, Report, Types, Process, Objectives and Advantages." *Business Management Ideas.* Accessed July 26, 2021. Web

[28] Bas van der Meer. "Four major disadvantages of no code that you must know." *Moqod.* April 26, 2018. Accessed July 27, 2021. Web.

[29] "Composer – Documentation". *Appgyver.* Accessed July 27, 2021. Web.

[30] Little, Wayne. Personal Interview. July 28, 2021

4. Security

Security for the purposes of this report will be defined as "... protection against the unauthorized access of data."[31] Due to the nature of the IAMJ study (working with personal health data), security is of utmost importance to ensure patient data is only reviewed by clinicians and those in academia who need to see it for research purposes. The project ensures security through the built-in security on the Xano platform, built-in security on the Appgyver platform, and close monitoring by the UHWI IT Department.

Xano ensures the security of the data stored on its platform through Information Security, Quality Management, and single-tenancy architecture. The International Organization for Standardization (ISO) promotes "... worldwide propriety, industrial, and commercial standards."[32] They have several certifications that determine whether a company is meeting international standards when it comes to data security. Xano has both ISO 27001:2013 which covers Information Security and ISO 9001:2015 which covers Quality Management Systems. Because Xano has the ISO 27001:2013 certification, patient data is better protected against cyber-attacks and data leaks.[33] Under ISO 9001:2015, Xano is more customer-focused and has a commitment to continuous improvement of the platform and its security.[34] Finally, Xano uses single-tenancy architecture, which means that IAMJ as a user is the only one on the server, and resources will be solely dedicated to IAMJ's uses.[35] This means that if another Xano user has a security breach, it won't be able to affect the security of IAMJ's Xano instance.

Though the security infrastructure of the database software is the most important link in protecting against a data breach, the front-end builder used for this project, AppGyver, also has rigorous security regulations in terms of protecting customer data. All AppGyver's sub processors (Amazon Web Services, MongoDB Cloud, RedisLabs, Google Analytics, etc) comply with the European Union's General Data Protection Regulations (GDPR). Though the GDPR is EU-centric, and AppGyver is a European-based software company, the law contains provisions pertaining to the transfer of data outside of the EU.[36] Additional provisions of AppGyver's privacy and data protection policy include "AppGyver is obligated to comply with the GDPR regardless of the contents of this Agreement", "AppGyver shall , after ninety (90) days from the termination of the Agreement destroy or anonymize the Customer Data...", and "AppGyver shall inform You in any writing of any Personal Data Breaches promptly after becoming aware of such."[37] Lastly, the security representatives of AppGyver believe "security

[31] "The Difference between Security and Privacy and Why It Matters to Your Program." *HIV.gov.* April 26, 2018. Accessed July 28, 2021. Web

[32] "ISO 27001:2013." *Xano Documentation.* Accessed July 28, 2021. Web

[33] Ibid.

[34] "ISO 9001:2015." *Xano Documentation.* Accessed July 28, 2021. Web

[35] "Best Practices." *Xano Documentation.* Accessed July 28, 2021. Web

[36] "Subprocessors." *Appgyver.com*. Accessed July 28, 2021. Web

[37] "Terms of Service." *Appgyver.com*. Accessed July 28, 2021. Web

misconfiguration" and "data exposure" to be the most common mistakes made by AppGyver end users when creating their applications.[38] The UHWI IT Department and the project team have met many times ensuring that these errors would not be made. The IT staff is also committed to maintaining this level of vigilance after taking over the project and ensuring that all the security requirements are met before, during and after the deployment process of the application.

The final security practice in place for IAMJ moving forward is constant communication with and monitoring by the UHWI IT Department. Their primary software developer currently is Mr. Wayne Little. The summer consultant team will do a transition of the Xano and Appgyver platforms to Mr. Little that consists of documentation and flow diagrams to communicate the software stack built over the summer. Mr. Little will be able to identify any security concerns and address clinician questions moving forward.

5. Privacy

Privacy for the purposes of this report will be defined as "...safeguarding of a user's identity."[39] Patient privacy will be accomplished through the separation of concerns within the database architecture and confidentiality agreements for all researchers before they are able to access patient data.

The database architecture currently only stores personally identifiable information (PII) in the patient table. All other tables that contain patient health information such as the health table and the step count table are only connected to the patient through a number ID. By separating out the information, the study can maintain anonymity between patients when examining and analyzing the data.

The IAMJ study will also ensure that anyone with possible access to the data signs a confidentiality agreement. This agreement was created using standard requirements and practices from UHWI with a review conducted by Brandeis researchers. See Appendix 3 for more information.

One future area of expansion for the privacy of this study is to include General Data Protection Regulation principles to make the privacy internationally compliant.[40] For the purposes of this report, the student consultant team ensured that they met all requirements for data privacy under the Jamaican Data Protection Act. The standards are listed in Appendix 5.

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[38] "Primer: Security." *Appgyver.com*. Accessed July 28, 2021. Web

[39] "The Difference between Security and Privacy and Why It Matters to Your Program." *HIV.gov*.

[40] "General Data Protection Regulation." *Intersoft Consulting.* Accessed August 9, 2021. Web

III. Future Work and Data Collection in the Medical Field

1. Recommendations

The goal for IAMJ beyond the summer is the continuation and survival of the project. This can be accomplished by creating a usable user interface (UI) and continuing to develop the user story functionalities.

UI Design

A critical part of the user stories is the user interface (UI) design and ensuring that it meets the needs of the Jamaican clinicians. After speaking with the UHWI IT Department, Mr. Wayne Little explained that if the interface is logical and easy to use, the clinicians will be able to use it.[41] Although Jamaica may prioritize different design choices,[42] Mr. Little assured us that the priority for the hospital is simplicity and utility, and that he would make any necessary changes to suit the needs of the clinicians. Mr. Little uses the SAP Fiori guidelines for user interface design, a standard originally from Australia[43]. The student consultants did not incorporate any specific SAP Fiori designs besides the built-in layouts on Appgyver to save development time, but this could be incorporated into future developments. Using a value comparison tool of the three countries (U.S., Australia, and Jamaica, see Figure 9)[44], the greatest difference is uncertainty avoidance and individualism. The risk in designing a UI that is culturally insensitive to Jamaican values is "Individualism" because Jamaicans have a higher sense of community than the U.S. or Australia. To mitigate this risk, the participant in-processing website was designed specifically to give the participants a sense that they are helping to improve the health of Jamaicans.

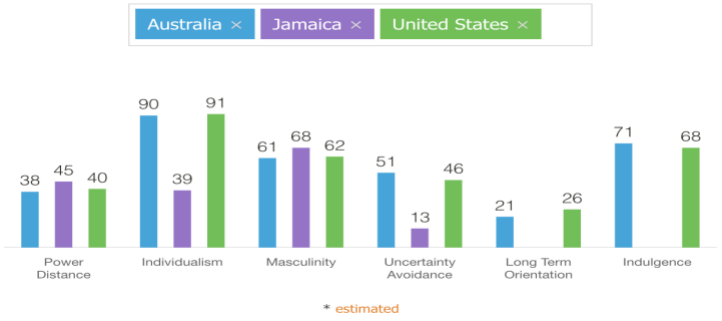

Figure 9: Country Value Comparison

[41] Little, Wayne. Personal Interview. July 28, 2021

[42] Cynthia, Risse. "Cross Cultural Interface Design." *Medium.* November 17, 2017. Accessed July 28, 2021. Web.

[43] "Explore SAP Fiori." Accessed July 28, 2021. Web

[44] "Country Comparison." *Hofstede Insights.* Accessed July 28, 2021. Web

User Story Functionalities

Many user stories were defined over the course of the summer from the perspective of clinicians and researchers. A "user story" is defined as an "… informal, general explanation of a software feature written from the perspective of the end user."[45] There are four main user stories not accomplished by the student consultant team that will be critical to the project's future success that are detailed below. The full list of user stories and the explanation of each can be found in Appendix 1.

- **The clinician needs to be able to automatically send incentives to the participants.** One of the roadblocks the team ran into when sending incentives to the participants was the difference in cell phone providers in Jamaica. The process for sending phone credits to participants is different depending on if they have Digicel or Flow. Because of this distinction, the summer student consultants manually calculated and sent incentives to each of the three PPP at the end of each week. In order to successfully expand the project in the future, an automatic infrastructure for calculating and distributing incentives should be developed.

- **The clinician should be able to monitor the medicines distributed to the study patients and the cost/timeline associated with each prescription.** One of the critical aspects of the IAMJ study design is determining if increased physical activity decreases the cost of care. In order to properly measure care costs after the study, the cost of medications before the study should be calculated. This presents a challenge because dosage measurements vary across types of medication (i.e. liquid insulin versus pills), and insurance plans vary across patients making the actual costs of care difficult to track.[46]

- **The researcher should be able to monitor trends in the study, such as: frequency of step goals met, changes in A1C measurements (as well as other health statistics).** Due to the focus on the patient in-processing and the clinician websites, the researcher view of the website does not have the full functionality that the summer consultant team had planned for. By giving the researchers the ability to view certain trends, they could make decisions to adjust the direction or details of the study in real time to satisfy the needs of the participants. This risk is mitigated by having the researchers sign confidentiality agreements through the hospital that allow them to view the study participant progress through the clinician view. However, as the study expands, it will be important to have a dedicated researcher application.

[45] Max Rehkopf. "User Stories with Examples and Template." *Atlassian: Agile Coach.* Accessed August 3, 2021. Web.

[46] "Pharmaceutical Situation in Jamaica." *WHO Assessment of Level II - Health Facilities and Household Survey.* September 2012. Accessed July 29, 2021. Web

- **The clinician should be able to view patient pre-existing conditions.**
  Like the second bullet above, pre-existing conditions of the study participants could affect the monetary amount of their care and present outliers in the data. It will be a crucial aspect of the data analysis to ensure there are no additional variables affecting readings that could affect the study results.

2. UHWI and Electronic Health Records (EHR)

One of the major future applications of this project is the development of a national Electronic Health Records system for Jamaica. Based on the lessons learned during this project, the summer student consultants recommend the prioritization of a simple integration mechanism, highly aligned / loosely coupled systems, and simple innovations that demonstrate the benefits of data-centric work.

The main feature the UHWI IT Department would like to see from a future Jamaica-wide EHR system is the ability to simply integrate multiple platforms.[47] Ultimately form and function can be revised, but if different systems are unable to talk to each other (as HiMS is currently unable to communicate with any outside application), the system is largely useless. By prioritizing the integration mechanisms, the Jamaican government would likely be able to save on development costs. It is clear from previous EHR research that lack of interoperability with current systems is one of the largest challenges to EHR expansion long term.[48]

A critical feature of a future EHR system for Jamaica is highly aligned and loosely coupled. The phrase (originally coined by Netflix) means that a flexible system is created that can meet the needs of different components within the organization while still adhering to the ultimate goals of the larger organization.[49] This applies to UHWI because there are different needs within each department. For example, the dermatology department could benefit from a function of a future EHR system that allows them to shade on a body diagram the skin areas that are affected, whereas this functionality may not be useful for other departments.[50] By structuring the IT department so that a single person is dedicated to each department in the hospital while maintaining centralized goal setting and infrastructure, the EHR could better meet the needs of the entire country's healthcare system.

While there are many keys to success when attempting to bring a data-centric culture to an organization, perhaps the most powerful for the Jamaican hospital system at this time is the idea of simple, useful, and rapid innovations.[51] By giving developers the opportunity to experiment and practitioners a chance to see the power of data, it is more likely that leaders within the hospital system otherwise unfamiliar with positive data practices would be supportive of making changes to further data development within the Jamaican healthcare system.

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[47] Wayne Little. Personal Interview, July 27, 2021.

[48] Yoshimasa Masuda, Donald S. Shepard, and Shuichiro Yamamoto. "Adaptive Governance on Electronic Health Record in a Digital IT era." *Twenty-fifth Americas Conference on Information Systems.* Cancun, 2019. Accessed July 29, 2021.

[49] Meyer, Erin and Reed Hastings. "No Rules Rules: Netflix and the Culture of Reinvention." Penguin Press: 2020. p. 318.

[50] Boyne, Michael M.D. Personal Interview, July 27, 2021.

[51]Myrthe Storm and Hans P. Borgman. "Understanding challenges and success factors in creating a data-driven culture." *53rd Hawaii International Conference on System Sciences.* 2020. Accessed July 29, 2021. Web

IV. APPENDICES

1. User Story Summary
2. Works Cited
3. Confidentiality Agreement
4. Contact List
5. Jamaican Data Privacy Act

1. User Story Summary

Agile User Story Evaluation

Number	User Story	Tractability (1=highest, 3=lowest)	User priority, (1= highest, 3=lowest)	Average Score (Lowest is best)	Completed?
1	A clinician should be able to enter health data for participants during their visits	1	1	1	X
2	A participant needs to be able to fill out their own data when entering the study	2	1	1.5	X
3	A clinician needs to update participant data as necessary (new entry after follow-up visits)	2	1	1.5	X
4	A clinician wants to be able to review step counts and A1C levels of patients over time to monitor their progress	2	1	1.5	X
5	A clinician needs to see which participants are owed what amount of incentives	2	1	1.5	X
6	**A clinician needs to send incentives to the participants**	2	1	1.5	
7	**A researcher wants to see updates on average participant step count and performance (% at target) over time (full study view)**	1	2	1.5	
8	**A researcher needs to be able to review step counts and A1C levels of patients over time to monitor their progress**	2	1	1.5	
9	**A clinician needs to see each patient's number of months since his/her last clinic visit**	2	1	1.5	
10	**A clinician needs to see each patient's number of months since his/her last A1c test**	2	1	1.5	
11	**A researcher needs to see each patient's number of months since his/her last clinic visit**	2	1	1.5	
12	**A researcher needs to see each patient's number of months since his/her last A1c test**	2	1	1.5	
13	A clinician wants to logon to the platform to maintain data security / privacy	1	3	2	X
14	A clinician want to automate BMI of patients based on height and weight inputs	2	2	2	X
15	A clinician should be able to input and view patient complications with diabetes seamlessly in a free-form notes section	1	3	2	X
16	**A reseacher needs to be able to see patient data without seeing their names (only viewed by participant ID)**	3	1	2	
17	A clinician needs to send periodic reminders to participants (can be daily to start and rolled off later on)	3	3	3	X
18	**A clinician needs to be able to see what medications patients are on and when they were perscribed in the study data base**	3	3	3	
19	**A reseacher wants like to know the total monthly costs of the perscribed medications**	3	3	3	

Figure 10: User Stories Overview

Figure 10 above shows the user stories the summer student consultant team accomplished versus the ones that were not completed (shown in bold). Below is a summary of each user story not accomplished:

- **A clinician needs to send incentives to patients.** This is important to the study to allow the study to expand more efficiently. At this point, incentives are calculated and sent manually (which is manageable for three participants), but automation of this process will be critical for more people. Working with Flow and Digicel IT support could lead to development of an API call or automation through Xano.

- **A researcher wants to see updates on average participant performance.** Maintaining average readings during the study will better inform researcher decision making over the lifetime of the study. Potential roadblocks to this user story include consistency between Xano and Appgvyer as records are updated over time. Keeping this functionality separated from the clinician website will be beneficial to keep the design of both applications simpler.

- **A clinician needs to see the number of months since a participant's last visit.** This is critical to ensure that participants are seen every three months to get regular interval A1C readings. This user story will likely be another attribute in the health data table. Calculations can be done to display when a patient is due to schedule an appointment. Potential risks to this is ensuring that appointments for participants within the larger study are staggered as to not overwhelm the diabetes clinic with too many people at once.

- **A researcher needs to see patient data without seeing names.** To protect participant privacy, an added functionality of the researcher dashboard is to display general trends within participant data collection without displaying participant names. This is beneficial because it would allow researchers to make decisions about the study without being affected by gender or age biases. To mitigate this risk, researchers are required to sign a privacy agreement regarding the confidentiality of patient data.

- **A clinician needs to see what medication patients are on.** Determining what diabetes mitigate methods the patients are using is critical in determining how much of an effect step count and incentives have on decreasing the cost of diabetes. Medications can also affect A1C levels, so clinicians need to know the medications to better advise participants in their diabetes management.

- **A researcher wants to know the total monthly costs of prescribed medications.** A key aspect of the study is to determine if increasing daily step count decreases the overall cost of care. Establishing monthly costs of medications is critical to determining if those costs go down after the study. One potential roadblock is the cost difference between public and private healthcare in Jamaica as well as if participants have health insurance or not. This could be an additional attribute in the patient table to mitigate this risk.

- **Color coding of health readings to give clinicians a better idea of which pieces of participant health data are normal or need attention.** Finally, color coding the clinician and researcher dashboard could provide better visual feedback as to which participants are meeting step count goals, maintaining health indicator readings, and scheduling regular appointments. The summer student consultant team did not explore design steps in Appgyver, so one potential risk is the time it would take to learn how to color code data stored in Xano.

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3. Confidentiality Agreement

CONFIDENTIALITY AND NON-DISCLOSURE AGREEMENT - IAMJ

The University Hospital of the West Indies

This agreement is intended to protect the privacy of all information at the University Hospital of the West Indies (hereafter referred to as **the Hospital**) whether this information is in the form of documents or electronic form. Each person accessing information at the Hospital holds a legal position of trust regarding this information and must recognise the duty to preserve the security and confidentiality of this information. During the course of the Incentivized Activity Monitoring Study (IAMJ), any persons who have access to patient data will sign and return a copy of this agreement.

Confidential Patient Information includes: All information received by the Hospital from patients that is considered by the patient to be confidential or that ought to be considered to be confidential from its nature or from the circumstances surrounding its disclosure. Any individually identifiable information regarding a patient's medical history, mental or physical condition or treatment, as well as the patient's records, test results, conversations and financial information.

I understand and acknowledge that:

1. I will not at any time during or after my assignment to the Hospital disclose confidential information to which I have or had access in any form (ie electronic media, paper, photograph, video) to any unauthorized individual.
2. I will not access any medical record I am not legally authorized to, including but not limited to the medical record of any family member, member of staff of the University of the West Indies (UWI) or Hospital, or fellow student.
3. I will respect the confidentiality of any reports or records and handle, store and dispose of these documents appropriately.
4. I will not access or request data on patients for whom I have no clinical relationship
5. If I have reason to believe that the confidentiality of the software stack has been compromised, I will report it and ensure that security measures are enacted again.
6. I will comply with all policies and procedures and other rules relating to confidentiality of information and log-ins
7. I agree to discuss confidential information only in the clinical/Hospital setting and only for academic related purposes and not to discuss such information outside of the clinical/Hospital setting or within hearing of other persons who do not have a need to know about such information
8. I understand that I may be subject to legal penalties (both civil and criminal) if I violate this agreement and any violation shall constitute grounds for severe disciplinary action, including the requirement to withdraw from the Faculty of Medical Sciences, UWI.

By signing this, I agree that I have read, understood and will comply with this Agreement.

_____ _____ _____

Name Date Signature

4. Summer Organizational Flow Chart / Contact List

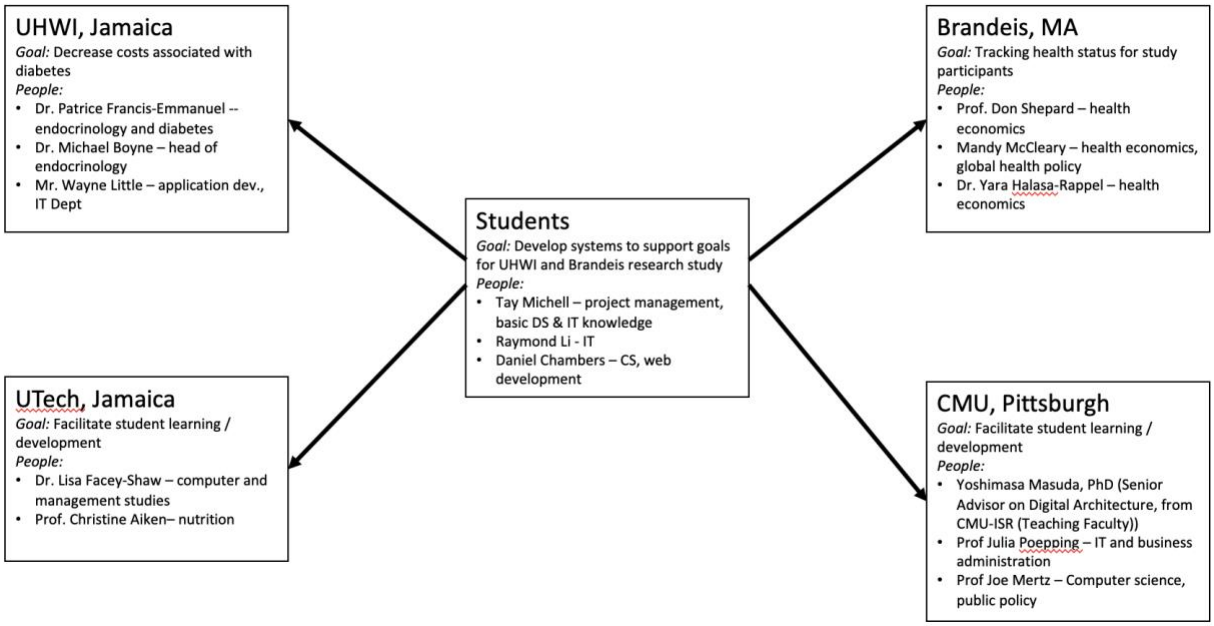

Figure 11: Summer Contact Flow Chart

- Student Consultants:
  - Tay Michell - tmichell@andrew.cmu.edu
  - Raymond Li - rli3@andrew.cmu.edu
  - Daniel Chambers - daniel_chambers15@outlook.com
- University Hospital in the West Indies:
  - Dr. Boyne - michael.boyne@uwimona.edu.jm
  - Dr. Francis - patrice.francis05@uwimona.edu.jm
  - Mr. Little - Wayne.little@uhwi.gov.jm
- Brandeis University:
  - Professor Shepard - shepard@brandeis.edu
  - Dr. Halasa-Rappel - yara@brandeis.edu
- Carnegie Mellon University:
  - Dr. Yoshimasa Masuda - ymasuda@andrew.cmu.edu
    - http://execed.isri.cmu.edu/faculty/masuda-yoshimasa.html

5. Jamaican Data Privacy Act

There are eight standards in the Jamaican Data Privacy Act of May 2020; below are the standards and how they apply to our project:[52]

1. Personal data should be processed fairly and lawfully -- each study participant will give consent before participating in the study
2. Personal data shall be obtained for one or more specified lawful purpose -- the lawful purpose of the study is to monitor step count for a decrease in the harmful effects of diabetes
3. Personal data shall be adequate, relevant, and limited to what is necessary for the purposes for which they are processed -- Beyond step count, the only pieces of data collected are those deemed necessary by the diabetes specialists
4. Personal data shall be accurate and when necessary, kept up-to-date -- step count will be updated on a daily basis and checked regularly by researchers
5. Personal data processed for any purpose shall not be kept longer than is necessary by that purpose -- future researchers will work with UHWI IT Department to ensure data is not kept longer than necessary
6. Personal data shall be processed in accordance with the rights of data subjects under this Act -- any and all questions will be answered by referencing the Act throughout the study or consulting the UHWI IT Department.
7. Appropriate technical measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data -- privacy will be maintained by using secured, trusted software. If there is any breach of personal data, the participants will be notified immediately.
8. Personal data shall not be transferred to a State or territory outside of Jamaica unless that State or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data -- information is being transferred out of Jamaica for the purposes of research. By using the software we have laid out in the report below, data privacy will be maintained.

[52] "The Data Protection Act, 2020." *Jamaica Parliament*. May 2020. Accessed Jun 14, 2021. Web.