

ECE 1778 Final Report
CIRCCulate: Communication In Relation to Chronic illness Care

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1. Introduction and Goal of the App: What is CIRCCulate?

CIRCCulate stands for Communication In Relation to Chronic illness Care. The goal of our app is to enhance patient autonomy and family involvement in healthcare management to improve outcomes for patients with chronic illnesses. This multi-user app is designed for patients and family members to coordinate chronic illness management and responsibilities through the following four features*.

- Shared calendar
- Shared library of audio recordings and audio to text transcripts of medical appointments
- Shared “timeline” for posting updates to all users
- Shared advance care plan (ACP) which identifies and documents who the patient’s substitute decision maker (SDM) is and any preferences for future health care that they have

*These features will be described in full in the section dedicated to the *statement of functionality* of the app.

Why: Patients living with chronic illnesses experience significant cognitive impairment which limits their ability to understand health information (1). Because of this, they rely heavily on social support in order to manage their illness and make important healthcare decisions (1). Research demonstrates that patients often have limited understanding of their illness and treatment options and may not comprehend all the information provided to them during their healthcare encounters (2). Because of this, patients are encouraged to bring someone to appointments with them to take notes and ask questions (3), however due to the nature of scheduling, frequency of visits, and the number of specialists being seen, this is often not possible. This app seeks to fill this gap by allowing recordings and transcripts of appointments to be shared with family members and updates to be provided via a shared timeline so all family members can be involved in care management and decision-making to the best of their ability.

Managing patients with multiple complex chronic conditions is an immense responsibility, and this burden is often shared between multiple family members. Unfortunately, there are no tools that currently exist to support the sharing of information between family members, nor any apps that support patients who would like to maintain their own records of their healthcare visits to share with their social support circles. This means important information is often being shared through informal channels (text, email, written notes etc.) with crucial details lost in the exchange between family members. Additionally, because there is no universal electronic health record in Ontario or Canada, different providers are often using different health record systems and are unable to access notes from other providers. This means that patients and family members are often caught providing crucial details of their health history and treatment plans to various providers, without a method to maintain their own record. This ultimately leads to challenges making decisions, especially for patients who may not be able to speak for themselves. CIRCCulate integrates chronic healthcare management,

family decision-making and advance care planning in order to provide a holistic record of the patient (and family) experience that will support self-advocacy and improved health outcomes.

2. Statement of Functionality & Screen Shots from App

2a. Statement of Functionality

i. Shared calendar:

- a. Enables creation of "events" where users can sign up for events and tag events with date and time, as well as location which is mapped by Google maps. There is also a section to include notes that allows users to identify what is required in the event (i.e. the patient must be fasting for 12 hours before the test, the patient cannot have caffeine for 48 hours before the test, etc.)
- b. Notification system: notifies users when a user signs up for events that they are able to support (i.e. if they can accompany the patient to an appointment) and also notifies users when new data has been added to the app such as appointments, audio recordings, and timeline updates.

ii. Shared library:

Allows users to record medical appointments using microphone and automatically creates a text transcript of the encounter, which can be saved in the library and posted to the timeline as an update. This allows family members to have access to conversations if they are not able to attend appointments and develop a record of visits.

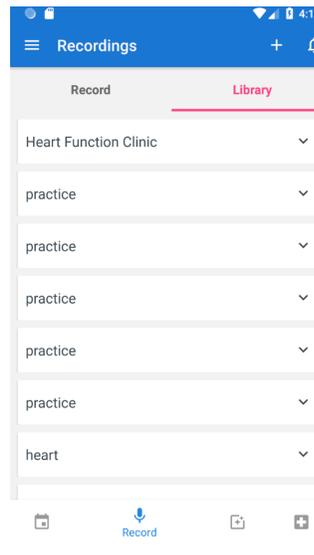
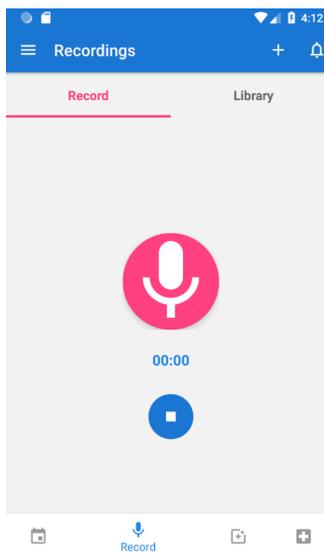
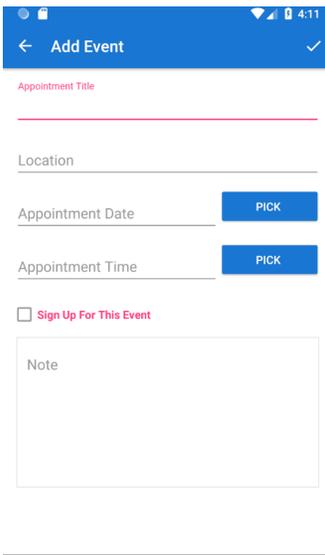
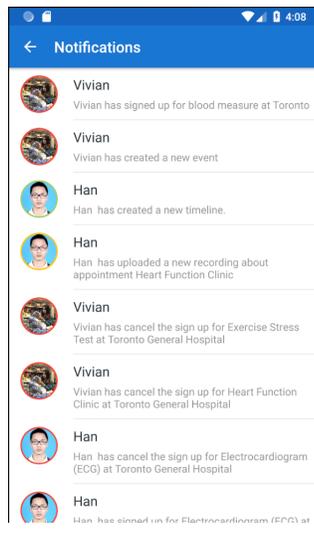
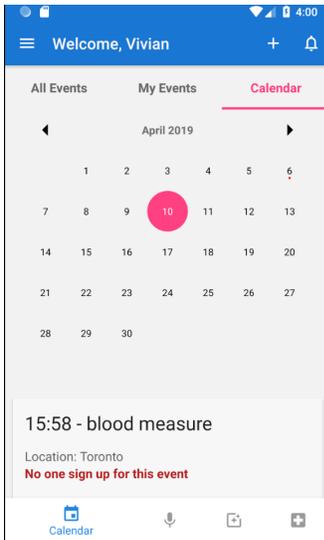
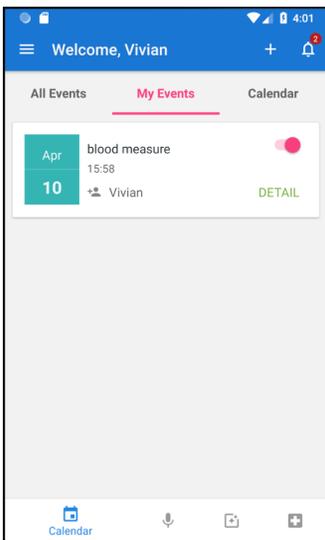
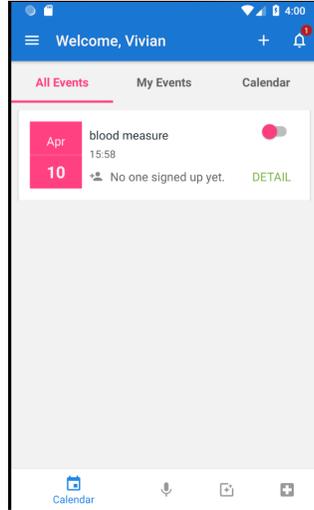
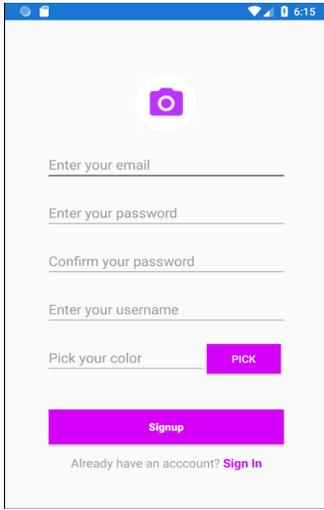
iii. Shared timeline:

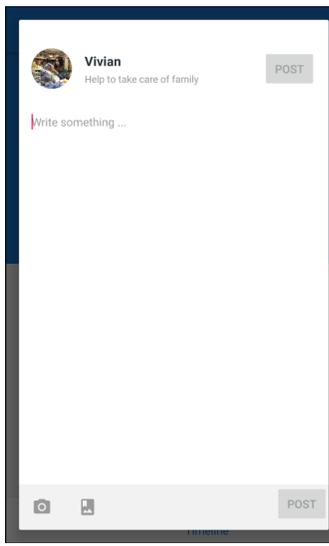
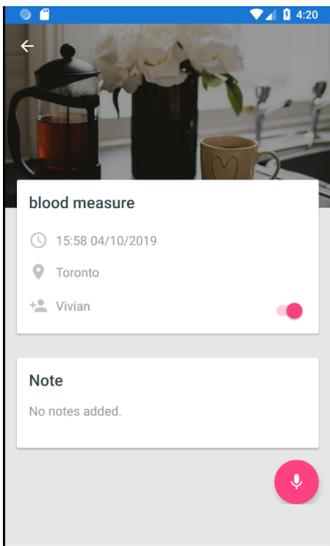
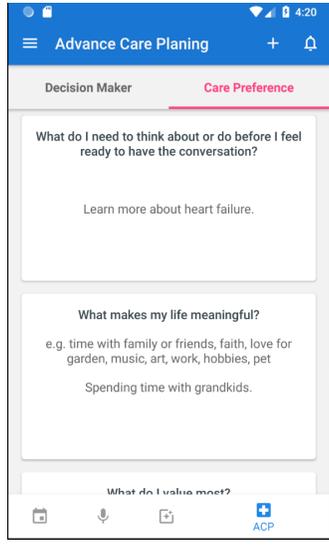
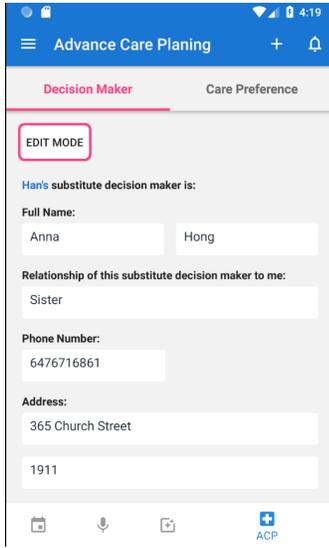
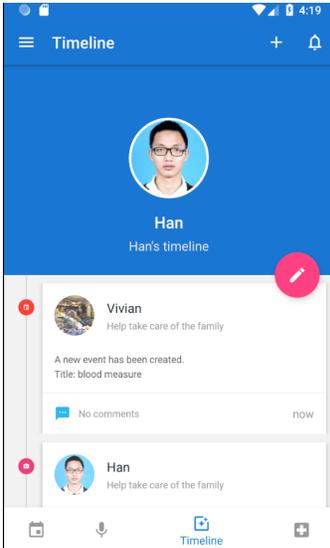
Running updates of health status of the patient where all users can provide an update in the form of a posting. Posting can include text, photo, video and the timeline is also updated when new events are added to the shared calendar.

iv. Shared advance care plan (ACP):

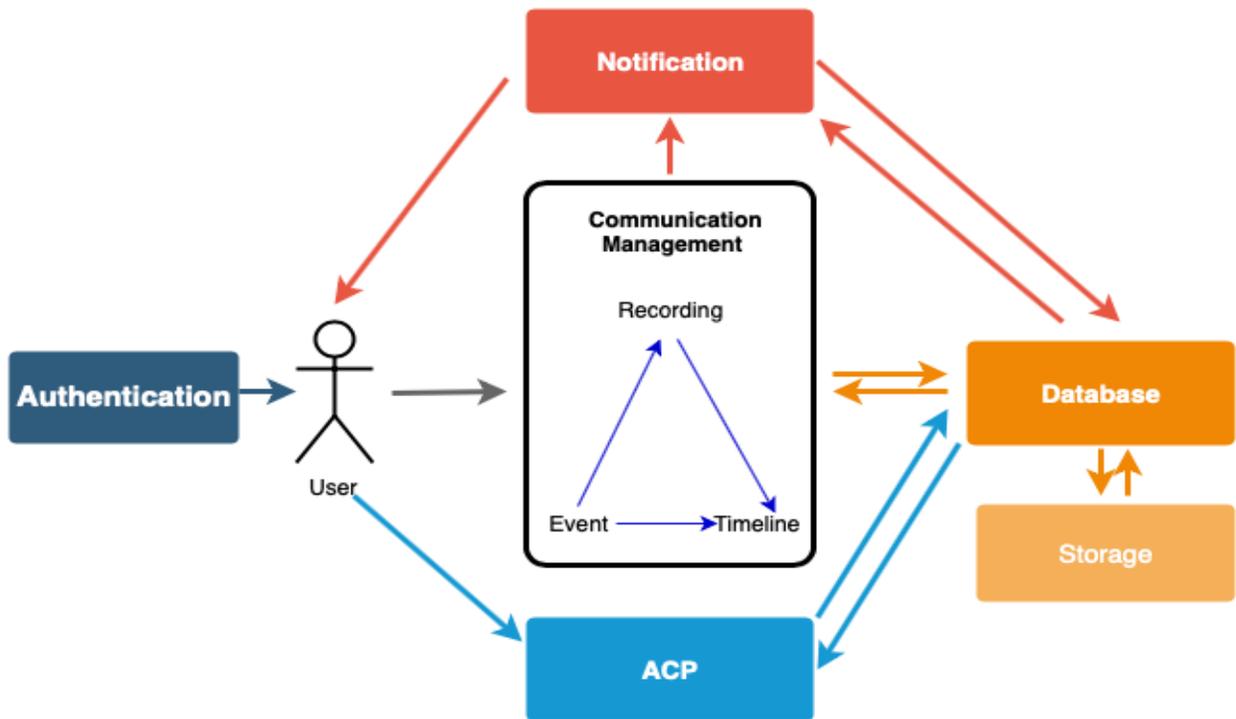
- a. Allows patient to identify and document who their substitute decision maker (SDM) is.
- b. Allows patient to identify and document any preferences for future health care that they may have. This information is accessible to all users who may be helping to make healthcare decisions if patients cannot speak for themselves.

2b. Screenshots from App





3. Overall Design – Block Diagram & Description of Design



Through authentication, the user enters the app. The input from the user comes from two main blocks: communication management and ACP. Within communication management, there are three functions: recording, event and timeline. A new event created will be posted to events list, to the timeline and the title will be available for selection when the patient wants to record this specific encounter. A new recording will update to the timeline as well. As all input are stored in database, a Google cloud function server will monitor the database related to communication management and send notifications once there is any change. The notification system is also linked to the database and provides output to users as an alert so that users can better interact with each other.

4. Reflection

From a specialist perspective, it did take time to finally land on app concept so we had to be flexible and open to changing ideas based on what was feasible, what already existed in the healthcare app landscape, and what would be most beneficial to the target audience. Additionally, I may have taken more time at the beginning to paint picture of the target audience for the programmers. I think by doing this and outlining how app would be used in the daily life of patients and families participating in care management, we would have saved time in the design and development process, as I found it important to use examples to communicate why certain things needed to be designed a specific way.

From a programmer perspective, we extended Android development skills and got lots of hands-on experience. In addition to technical knowledge, we explored user experience design and learned to collaborate over negotiation. We also learned that agile development method is important for project management. What we would change is that we would communicate more with our specialist. When we came with something unclear, occasionally we just followed our own instincts and did not discuss with the specialist in time, which led to changes later on.

As a group, the spiral framework was very useful for us as it allowed us to divide project into distinct small pieces that were attainable. This process kept us on track regarding our timeline, and actually allowed us to develop more than we initially thought would be possible in the timeframe. This approach also encouraged progress as it was exciting to see each piece of the app become functional, and then we could work on connecting them together. Finally, weekly meetings and frequent communication regarding progress were crucial to the success of this project.

5. Contribution by Each Group Member

Tieghan (Specialist)

As the group specialist, I contributed to this project in a number of ways. First, I worked through different conceptualizations of the idea, synthesized research in the field of chronic illness management and advance care planning and utilized my knowledge and expertise in the field to help us land on an app idea that would be meaningful and useful to our population of interest. Secondly, I sought user feedback and discussed features and functionality with patients and family members of people living with chronic illness. After the general structure and plan for the app was agreed upon, my role continued as the overall project manager where I was responsible for a variety of tasks. I provided continued consultation with programmers regarding functionality, design and user interface and experience. I managed group coordination, set weekly meetings, and supervised task tracking on shared Google Docs. I was also primarily responsible for presentation preparation, slide design, and narrative development as our group consistently sought to develop realistic narratives to demonstrate how this app would be used in daily chronic illness management. Finally, I was responsible for the majority of writing, editing and submission of written assignments and reports throughout the course.

Han (Programmer)

Before spiral 2, I designed the overall software structure, for example, the code structure for the fragments in host activity and sub-fragments in host fragment. Then I designed the database schema for user and event object. After that, I implemented the calendar fragment and add event functionality. During spiral 2 and spiral 4, I implemented the notification system using Google Firebase cloud messaging and cloud function. Then I used Google's speech to text API to transfer recording to text. After that, I designed the recording schema for the database reference.

During spiral 4 and the final presentation, I implemented the timeline feature, for example, I designed the timeline page, as well as the add timeline dialog. Then I designed the database schema for timeline object. I was also responsible for the health care preference in the ACP feature, including adding new health care preference and display patient's care preference.

Yixuan (Programmer)

Before spiral 2, I participated the software structure design process and made the decision with Han. I chose our app UI style and implemented sign in and sign up page. Later I designed how each item in event recyclerview should looked like. I also implemented the detail page. During spiral 2 and 4, I first changed the raw. audio in the database to wav. format file. Then I implemented the recording library page with media player playing the audio. I also created another activity which the user can click to see the transcripts. Additionally, I implemented some small functions such as progress bar, delete and toggle.

During spiral 4 and the final presentation, I added the comment feature to the timeline, designed the comment schema and changed the timeline object model. I also designed a comment page for users to see all comments. Finally, I took responsibility for the substitute decision maker component of the ACP feature including text entry and display functions, and I designed a drawer to the app.

6. Specialist Context

This app is a contribution to my field because it focuses beyond the individual patient and acknowledges that autonomy and self-directed decision-making is experienced relationally (4, 5). This means that patients rely on social support to manage their illnesses and make their healthcare decisions (4). This is important because our current model of autonomy and decision-making in Western healthcare systems focuses only on the individual patient and does not encourage or support family involvement in management and decision making (4-6). On a broad level, this app also responds to the call for patient empowerment and self-management (7, 8) by actually providing a tool that allows family members to act as advocates. This app supports the autonomy of patients living with chronic illness by giving them a means to track, record and communicate about their illness management.

Finally, this project is especially unique because it combines family healthcare coordination with advance care planning. Traditionally, advance care plans have been stand-alone documents that are decontextualized from the realities of patients living with chronic illnesses (9). This ultimately limits their utility, as they are disconnected from the daily experience of chronic illnesses and the myriad of decisions that must be made by patients and family members (9). Additionally, family members often do not have access to these documents when they are required, and there can be significant legal and ethical confusion regarding how to proceed with decision-making if a patient is unable to speak for themselves. Combining these two components of healthcare

management into the CIRCCulate app is a novel method that allows all users to be aware of important information in an accessible way and supports health decision-making in a way that truly resonates with the experience of patients and families.

7. Future Work

1. Improving calendar functionality

This enhancement would allow the “calendar” portion of the app to sync with Google calendar (and other calendar apps) to limit double entry of events and improve functionality. This would likely involve intensive work on the programming side in order to achieve, however it would greatly benefit patients so would be worthwhile if we were to move forward with this app. Additionally, there should be a small sign that allow users to identify the days where there are events scheduled (visible from the Calendar page). This was attempted using calendar libraries from GitHub but was not successful. We decided to move onto more important features but would like to pursue this in the future.

2. Further development of advance care planning (ACP) feature

The advance care planning feature could be greatly expanded upon to further benefit patients with chronic illnesses. This section could combine text boxes and audio/video recordings done by patient (with prompts) to outline how the patient would like decisions to be made in the case they cannot speak for themselves. Additional aspects of this feature could include providing education regarding end-stage chronic illness management and palliative care to support patients and families making who are making challenging end-of-life decisions. Another aspect of this work could include interactive value-identification exercises, which would help patients and families understand what is most important to them in the context of their illness and the treatment decisions they are making.

3. Developing a portal system

Developing a portal system would allow import of healthcare records (i.e. diagnostic imaging, blood work, referrals) and well as allow healthcare providers to access system to provide updates to patients and family members could be a way to enhance the functionality of the app. This suggestion has been made frequently in discussions with patients and family members regarding this app. Although the benefit is quite clear, it would likely be the most challenging aspect of the app to implement and fully utilize, due to the legalities of medical records, confidentiality legislation, and having buy-in and support from healthcare providers.

4. Improve user interface design and user experience

Finally, the colours and overall design of the app could be improved, and flow of app usage could be streamlined.

8. Posting each of the following on the Course Website:

- 1. Video of final presentation**
- 2. Report**
- 3. Source code**

Tieghan - I am okay with 1, 2 & 3 being made public.

Yixuan - I am okay with 1, 2 & 3 being made public.

Han - I am okay with 1, 2 & 3 being made public.

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